



## DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

### Doctorate in Clinical Psychology: Main Research Portfolio

1) Exploring the relationship between perfectionism and fatigue: Informing psychological models of Chronic Fatigue Syndrome; qualitative analysis of the information needs of parents of children with Cystic Fibrosis prior to first admission; Parkinson's Disease. 2)A 3)Psychological factors in

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Research Portfolio Submitted in Part Fulfilment of the Requirements for the Degree  
of Doctorate in Clinical Psychology

Vera Christina Fixter

Doctorate in Clinical Psychology

University of Bath

Department of Psychology

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## Table of Contents

Critical Literature Review .....	6
Abstract.....	7
Introduction .....	8
Method.....	13
Results .....	16
Discussion.....	35
References .....	41
Service Improvement Project.....	51
Abstract.....	52
Introduction .....	53
Method.....	55
Results .....	58
Discussion.....	66
References .....	69
Main Research Project .....	73
Abstract.....	74
Introduction .....	75
Method.....	78
Results .....	84
Discussion.....	91
References .....	95
Executive Summary .....	102
Connecting Narrative .....	104
Acknowledgements .....	112
Appendix A: Instructions for authors for Critical Literature Review .....	113
Appendix B: Instructions for authors for Service Improvement Project .....	123
Appendix C: Information relevant to ethical review (SIP) .....	133
Appendix D: Service recommendations (Service Improvement Project) .....	134
Appendix E: Feedback to service (Service Improvement Project) .....	136

Appendix F: Instructions for authors for (MRP) .....	138
Appendix G: Information relevant to ethical review (MRP).....	133
Appendix H: Participant Information Sheet.....	147
Appendix I: Consent Form.....	151
Appendix J: Questionnaire Measures.....	153

## Figures

### Critical Literature Review

Figure 1. Flow chart of study selection	15
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## Tables

### Critical Literature Review

Table 1. Summary of non-clinical studies	28
Table 2. Summary of clinical studies	30

### Service Improvement Project

Table 1. Semi-structured interview questions	57
Table 2. Participant quotes	59

### Main Research Project

Table 1. Means (SDs) of sample characteristics, PD-related variables & questionnaire measures	85
Table 2. Means (SD) for the cognitive and physical tasks across groups	88
Table 3. Participants' subjective ratings (Mean and SD) of performance	89
Table 4. Stepwise regression results	90

## **Critical Literature Review**

### **Exploring the relationship between perfectionism and fatigue: Informing psychological models of Chronic Fatigue Syndrome**

Vera Christina Fixter

Doctoral Programme in Clinical Psychology, Department of Psychology, University of Bath, Claverton Down, Bath, BA2 7AY, Tel: 01225 385506, Email: [vch23@bath.ac.uk](mailto:vch23@bath.ac.uk)

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## **Abstract**

Over the last few decades researchers have attempted to explore the relationship between perfectionism and Chronic Fatigue Syndrome (CFS). Both cognitive behavioural and psychodynamic models of CFS include perfectionism as a key contributory factor in this condition. This review investigates the empirical evidence for a relationship between perfectionism and fatigue to inform psychological models of CFS. A systematic search of five electronic databases (SCOPUS, PubMed, PsychNET, Science Direct and Web of Science) was performed, yielding 726 articles; 20 of which met the inclusion criteria. This review provides a synthesis and critical evaluation of the literature, drawing on multi-dimensional models of perfectionism. Findings provide support for the psychological models of CFS, indicating that perfectionism is significantly associated with fatigue, typically with small to moderate correlations ( $r=.12-.44$ ). More specifically, negative perfectionism and in some cases positive perfectionism are positively correlated with fatigue. Prospective research supports the role of perfectionism as a potential risk factor for fatigue and there is some evidence to suggest the role of depression and repetitive negative thought in this relationship. Psychological interventions, such as cognitive behavioural therapy (CBT) focussing on the remediation of perfectionism, may be of benefit to patients with CFS. Furthermore, clinicians may benefit from paying greater attention to depression and repetitive negative thinking, given their potential role in mediating the relationship between perfectionism and fatigue.

**Keywords:** Perfectionism; Chronic Fatigue Syndrome; Fatigue; Cognitive Behavioural Model; Psychodynamic Model



## **Introduction**

### **Clinical aspects of Chronic Fatigue Syndrome**

Chronic Fatigue Syndrome (CFS) is a debilitating condition, characterised by persistent and unexplained fatigue of at least six months duration, resulting in severe impairments in daily functioning (Holmes et al., 1988; Sharpe et al., 1991). Although the predominant feature, fatigue is often accompanied by a range of other symptoms including generalised muscle pain, headaches and post exertional malaise (Fukuda et al., 1994). Prevalence estimates in the general population range from 0.5% to 2.5% (Reeves et al., 2007), with the average age of onset between 30 and 40 years (Jason et al., 1999; Lloyd, Hickie, Boughton, Spencer, & Wakefield, 1990).

The term CFS and the criteria for diagnosing the disease were introduced in 1988 (Holmes et al., 1988). Prior to this point, a number of illnesses with symptoms similar to those of CFS were reported, these included: neurasthenia, post-viral or post-infectious fatigue, Myalgic Encephalomyelitis (ME), Immune Dysfunction Syndrome and Royal Free disease (Wessely, 1994).

### **Causes and maintenance factors**

Over the years there has been much debate surrounding the etiology of CFS, with a number of theories having been proposed. Earlier theories focussed on the occurrence of symptoms suggestive of a psychiatric disorder or acute viral illness. However, subsequent studies have also indicated differences in a number of areas including brain structure and function, neuroendocrine response, immune function, and psychological attributes (Afari & Buchwald, 2014; Balachander, Rao, Sarkar, & Singh, 2014). There is evidence that CFS is unlikely to be caused by just one etiological factor but rather is multi-factorial (Wessely, Sharpe, & Hotopf, 1998). A bio-psycho-social model may explain the development of CFS, where disability results from the interplay between various predisposing and perpetuating factors. This review will focus on one of the proposed contributing factors: perfectionism.

## **Cognitive behavioural and psychodynamic models of CFS**

As previously noted, within the biopsychosocial model of CFS, one factor that may have a perpetuating and even predisposing role are the personality traits of those with the condition. The cognitive behavioural model of CFS by Surawy, Hackmann, Hawton and Sharpe (1995) provides one possible explanatory framework for understanding how personality traits may interact with an organic insult, such as an acute illness, to precipitate a cycle of psychological and behavioural responses that result in the development and maintenance of CFS.

According to the cognitive behavioural model, individuals at risk of developing CFS are thought to have pre-morbid personalities characterised by “a marked achievement orientation, perfectionism, high standards of work performance, responsibility and personal conduct” (Surawy et al., 1995, p.537). They are said to have a propensity to place great emphasis on the opinions of others, striving to meet their own and others’ expectations.

When faced with an event that challenges their ability to perform, assumptions regarding achievement, strength and personal worth are activated leading to an increase in activity. In the context of CFS, the precipitating event (e.g., acute illness) is said to place demands on the individual, leading to a depletion of personal resources and affecting their ability to cope. In an attempt to improve their situation, the individual tries to increase their level of activity, working hard to meet their desired goals. Unfortunately, this only leads to an exacerbation of symptoms and a subsequent reduction in activity.

According to the cognitive model, once a state of fatigue is established, cognitive, behavioural, emotional, physiological and social factors may act to perpetuate it. Importantly, the individual searches for an explanation for their fatigue. For many, concerns about the cause of their symptoms may favour a biological explanation. As time passes, repeated experiences of failure and fears of exacerbating symptoms serve to reinforce beliefs that the individual must have a chronic disease, resulting in emotional distress (e.g., anxiety and depression), inactivity and abandonment of

efforts to meet previous standards. The model suggests that it is the physiological changes that accompany this chronic state of emotional distress and inactivity that result in the ongoing symptoms of fatigue, poor concentration and muscle pain.

Psychodynamic theorists have furthered this, arguing that self-critical perfectionism may play a role in the precipitation and perpetuation of CFS by impacting adversely on the stress system and stress response. Van Houdenhove, Van Den Eede and Luyten (2009) hypothesised that the pathophysiological basis of CFS could involve a “switch” of the stress system from a state of over-drive to under-drive, leading to persisting impairments in the stress response and associated changes in pain regulation mechanisms and abnormal inflammatory activity. These researchers argued that this ‘switch’ results from chronic periods of over-activity, often triggered by an emotional and/or physical event. Further, they hypothesised that self-critical perfectionism may be one driving force behind high levels of over-activity. Thus, according to the cognitive and psychodynamic models, perfectionism is a key psychological variable in the development and maintenance of CFS.

## **Perfectionism**

Perfectionism was described by Hollender (1978) as “the practice of demanding of oneself or others a higher quality of performance than is required by the situation” (p.384, as cited in Shafran, Cooper, & Fairburn, 2002). Debate remains in the research literature as to the exact nature of the perfectionism construct. Initially described as a personality trait it has since been generally accepted as a cognitive process, involving the setting of high standards. Some researchers have maintained that perfectionism is uni-dimensional (i.e., clinical perfectionism; see Shafran, et al., 2002) while others have proposed that it is multi-dimensional (Frost, Marten, Lahart, & Rosenblate, 1990; Hewitt & Flett, 1991; Hewitt, Flett, Turnbull-Donovan, & Mikail, 1991), existing in multiple subtypes and presentations.

Factor analytic studies of the two main measures of perfectionism (both known as the Multi-dimensional Perfectionism Scale, MPS: Frost et al., 1990, Hewitt & Flett, 1991) typically indicate a two-factor model. In a recent analysis of existing studies, Dunkley, Blankstein, Masheb and Grilo (2006) concluded that perfectionism is

comprised of two related but independent factors. These are ‘personal standards,’ characterised by high self-standards and achievement striving, and ‘evaluative concerns,’ characterised by self-doubt and self-criticism. The former is linked to adaptive outcomes and the latter to maladaptive outcomes. This two-factor model, closely relates to the concepts of ‘positive’ or ‘healthy’ and ‘negative’ or ‘unhealthy’ perfectionism (Frost, Heimberg, Holt, Mattia, & Neubauer, 1993; Slade & Owens, 1998; Stumpf & Parker, 2000).

In the wider literature, positive perfectionism has been associated with high self-esteem and conscientiousness (Campbell & Di Paula, 2002; Stumpf & Parker, 2000). Conversely, negative perfectionism has been significantly correlated with a wide range of psychopathology including clinical depression, anxiety and eating disorders (Bardone-Cone et al., 2007; Fairburn, Cooper, & Shafran, 2003; Shafran & Mansell, 2001).

### **The assessment of perfectionism**

Two of the most widely used measures of perfectionism are the Frost Multidimensional Perfectionism Scale (Frost MPS: Frost et al., 1990) and the Hewitt and Flett Multidimensional Perfectionism Scale (Hewitt and Flett MPS: Hewitt & Flett, 1991).

The Frost MPS provides a score for six dimensions of perfectionism as well as a total score. The six dimensions are conceptually labelled as Concerns over Mistakes (CM), Personal Standards (PS), Parental Criticism (PC), Parental Expectations (PE), Doubts about Actions (DA), and Organisation (O). The Frost MPS has been found to have good evidence of construct, concurrent and discriminant validity. The internal consistency of the subscales range from .77 to .93 and is .90 for the total perfectionism score (Frost et al., 1990).

The Hewitt and Flett MPS comprises of three dimensions: Self-Orientated Perfectionism (SOP: this reflects setting high standards for oneself), Socially Prescribed Perfectionism (SPP: this reflects an individual’s concerns regarding others’ high expectations) and Others Orientated Perfectionism (OOP: this reflects

setting high standards for others). Evidence supports the test–retest reliability, factorial validity, predictive validity, and discriminant validity of the Hewitt and Flett MPS (e.g., Hewitt & Flett, 2004). The internal consistency for the subscales ranges from .74 to .88 (Hewitt & Flett, 1991).

In the past few decades, additional multi-dimensional perfectionism measures have emerged with adequate psychometric properties and different conceptualisations of perfectionism. The Almost Perfect Scale-Revised (APS-R: Slaney, Rice, Mobley, Trippi, & Ashby, 2001) is an empirically and factor analytically derived scale (Suddarth & Slaney, 2001; Wang, Yuen, & Slaney, 2009) assessing maladaptive and adaptive perfectionism. It includes a discrepancy scale to determine distress caused by the mismatch of standards and performance. Factor structure, reliability, and validity of APS–R scores have been supported in several studies, with internal consistency of subscales ranging from .80 to .90 (e.g., Grzegorek et al., 2004; Rice & Ashby, 2007). The Positive and Negative Perfectionism Scale (PANPS: Terry-Short, Owens, Slade, & Dewey, 1995) is an alternative measure, based on a two factor distinction between ‘normal’ and ‘neurotic’ perfectionism. Internal consistency for the subscales ranges from .81 to .83 (Haase & Prapavessis, 2004). Finally, the Child and Adolescent Perfectionism Scale (CAPS: Flett, Hewitt, Boucher, Davidson, & Munro, 1997 as cited in O’Connor, Dixon, & Rasmussen, 2009); derived from the Hewitt and Flett MPS (1991), is a commonly used measure of perfectionism in the childhood literature comprising of two dimensions, SOP and SPP. The CAPS has shown to have good internal consistency properties and adequate 1 week test–retest reliability (Castro et al., 2004).

#### *Other measures which include assessment of perfectionism*

Other measures that include an assessment of perfectionism include the Dysfunctional Attitudes Scale (DAS: Weissman & Beck, 1978) and the Depressive Experiences Questionnaire (DEQ: Blatt, D’ Afflitti, & Quinlan, 1976). The DAS is a measure of dysfunctional attitudes proposed to play a role in depression. It has a consistent two factor structure measuring (a) social approval and (b) perfectionism. The DEQ has been used by some researchers as a measure of self-critical

perfectionism and interpersonal dependency, and has good psychometric properties (Blatt, 2004; Luyten et al., 2011).

### **Aim of the current review**

The most recent review of the relationship between perfectionism and CFS (van Geelen, Sinnema, Hermans, & Kuis, 2007) concluded that there was inconsistent evidence to support the role of perfectionism in CFS. This review however focused on personality broadly, not perfectionism specifically, and findings were limited to patients with a clinical diagnosis of CFS. Further, since this review, the area of perfectionism research in fatigue has expanded significantly. This new body of research warrants a comprehensive examination.

The current review sought to provide a synthesis and critical evaluation, drawing on views in the literature that perfectionism in CFS may be more clearly distinguished utilising a two-factor model of perfectionism, characterised by positive and negative components (e.g., Kempke et al., 2011a). To the author's knowledge, this is the first review specifically exploring the relationship between perfectionism and CFS. It is anticipated that this review will inform clinical practice as well as highlight areas for future research.

## **Method**

### **Search strategy**

An extensive systematic literature search was conducted and a key word search of articles indexed in the SCOPUS, PubMed, PsychNET, Science Direct and Web of Science databases was performed on 1<sup>st</sup> January 2015. No date restrictions were applied. The computerised search used the following strategy: (perfect OR perfectionism OR perfectionistic) AND (fatigue OR “chronic fatigue” OR “chronic fatigue syndrome”). Search terms were subjected to thesaurus mapping in PubMed and PsychNET.

## **Inclusion and exclusion criteria**

Each article was screened for inclusion according to the following criteria: the article (i) included a standardised measure of perfectionism and fatigue, (ii) explored the relationship between perfectionism and fatigue (iii) was classified as primary research, (iv) was published in a peer-reviewed journal and (v) was published in the English language. Book chapters, conference abstracts, case studies, review articles, dissertation and theses abstracts were excluded from the search.

There is some evidence to suggest that fatigue is continuously distributed in the population (e.g., Pawlikowska et al., 1994) and therefore some of the factors contributing to CFS as suggested by the cognitive-behavioural model, may also be at work in fatigue at the less severe end of the spectrum (Lewis & Wessely, 1992). If this is the case then studies looking at perfectionism and fatigue in non-clinical samples may allow for predictions made by clinical models of CFS to be tested. With this in mind, the search included both clinical (i.e., patients meeting CFS criteria) and non-clinical (e.g., student) populations, and cross-sectional, case-control and prospective studies.

## **Selection of studies**

The initial database search yielded 957 articles: 726 after duplicates were removed. The titles and abstracts were then screened for inclusion. In cases where it was not clear from the abstract whether the article met inclusion criteria, the full-text article was reviewed. Electronic searches were supplemented by hand-searching reference lists of retrieved papers. Twenty studies met the inclusion criteria (see Figure 1).

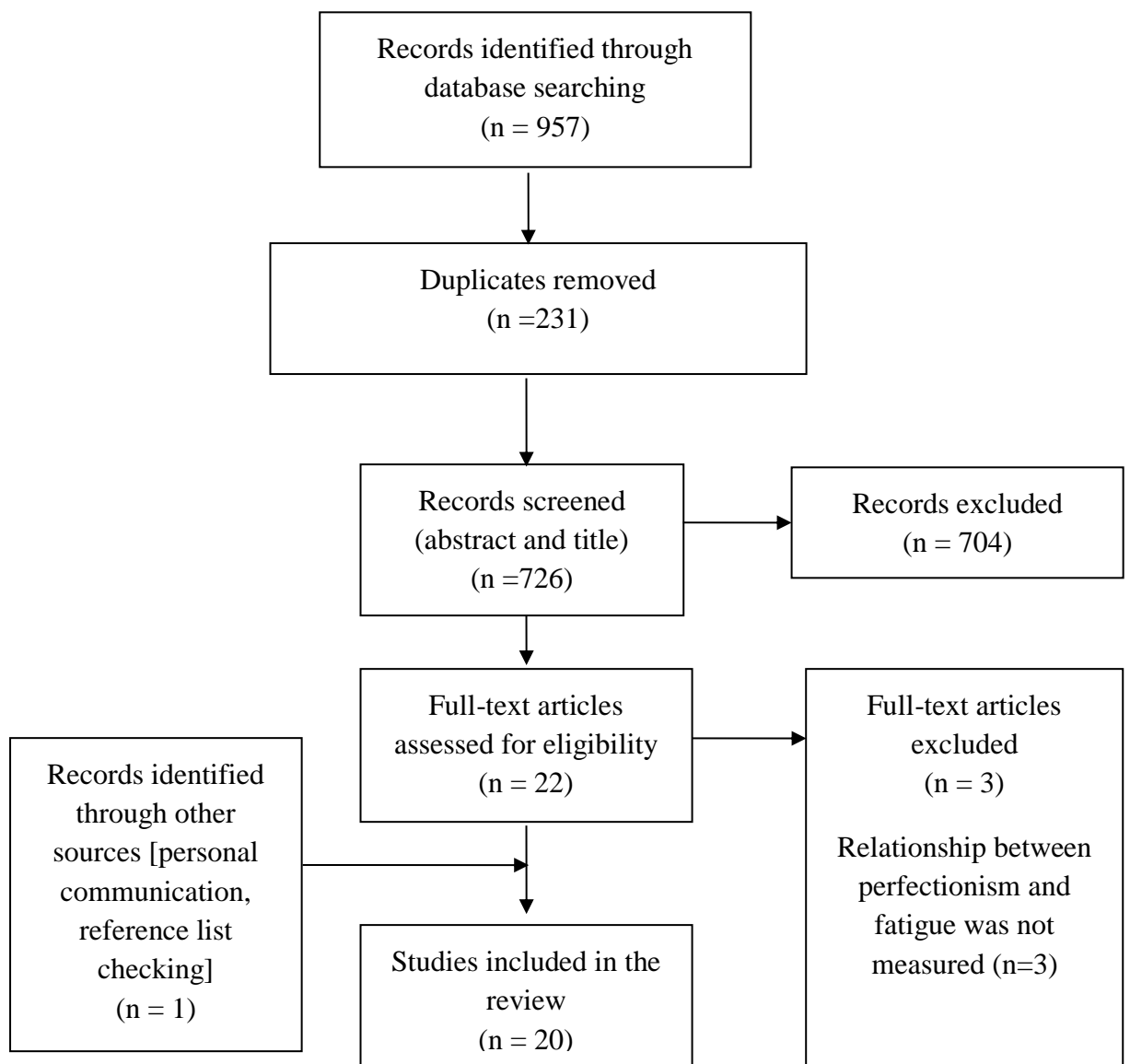


Figure1. Flow chart of study selection



## Results

This section seeks to synthesise key findings of the studies included in the current review in order to establish whether there is a relationship between the construct of perfectionism and CFS. See Tables 1 and 2 for a summary of findings.

### Cross-sectional correlational studies

#### *Non-clinical groups*

Five cross-sectional correlational studies exploring the relationship between perfectionism and fatigue in non-clinical samples were identified. Magnusson, Nias and White (1996) revealed significant small to moderate correlations between negative perfectionism (DA, PE) and increased mental and physical fatigue ( $r = .19-.30$ ,  $p < .05$ ) in a sample of 121 female nursing staff. Further, findings indicated a trend for positive aspects of perfectionism (i.e., PS) to be inversely related to tiredness, suggesting positive perfectionism may have a protective effect against fatigue.

Saboonchi and Lundh (2003) explored the relationship between perfectionism and somatic health in a population sample of 184 Swedish adults. Findings indicated that both positive and negative aspects of perfectionism (SOP and SPP) showed small but significant positive correlations ( $r = .18-.20$ ,  $p < .05$ ) with self-reported somatic complaints, specifically the 'Tension/Fatigue' subscale of the Somatic and Emotional Experiencing Inventory (SEEI: Lundh & Simonsson-Sarnecki, 2001). Further, the relationship between SPP and 'Tension/Fatigue' was significant only for women, raising the question "To what extent is the relationship between perfectionism and somatic complaints gender specific?". The relationship between negative perfectionism and fatigue was further supported by Macedo et al. (2009) who found a small positive correlation between SPP and fatigue symptoms ( $r = .23$ ,  $p < .001$ ) in a sample of 421 pregnant women.

Arpin-Cribbie and Cribbie (2007) attempted to shed further light on the relationship between perfectionism and fatigue by examining different components of fatigue (fatigue-related emotional distress, somatic symptomology, general fatigue and cognitive difficulties) separately. In a large sample of undergraduate students (N=307), perfectionism was found to significantly correlate with fatigue-related emotional distress ( $\beta = 0.13$ ,  $p < .05$ ) and cognitive difficulties ( $\beta = 0.18$ ,  $p < .05$ ) but not with general levels of fatigue or somatic symptomology. Depression and automatic negative thoughts were found to correlate more strongly than perfectionism with all four components of fatigue, suggesting that they may be more significant contributors to fatigue. Although these findings are interesting, this study is limited in that the analyses did not look at the individual dimensions of perfectionism; rather a composite measure was employed.

Finally, Macedo et al. (2015) investigated the potential mediating role of repetitive negative thinking in the relationship between perfectionism and fatigue in a sample of 788 university students. Perfectionism was measured utilising two composite trait perfectionism dimensions: Evaluative Concerns (EC) and Positive Striving (PS) derived from the Portuguese versions of the Frost MPS (Amaral et al., 2013) and the Hewitt and Flett MPS (Macedo et al., 2007). Findings revealed a moderate correlation between negative perfectionism (i.e., EC) and increased fatigue ( $r = .44$ ,  $p < .01$ ). When entered into a hierarchical regression model after perceived stress and social support, perfectionism scores (EC and PS) were found to account for additional variance in fatigue. Furthermore, mediation analyses revealed repetitive negative thinking to be a partial mediator of the relationship between negative perfectionism (EC) and fatigue and a full mediator of the relationship between positive perfectionism (i.e., PS) and fatigue. These findings suggest that the effect of negative perfectionism on fatigue was potentiated by repetitive negative thinking. In the case of positive perfectionism, a relationship with fatigue only existed when high levels of repetitive negative thinking were also present.

### *Summary*

The findings support the role of perfectionism as a consistent correlate of fatigue with repetitive negative thinking as a potential mediator in this relationship (Macedo et al., 2015). More specifically, the effects of negative perfectionism on fatigue

appear to be exacerbated by repetitive negative thinking and in the case of positive perfectionism, repetitive negative thinking is a necessary condition to the association between perfectionism and fatigue.

It is important to note however that most correlations reported above were small to moderate ( $r=.18-.44$ ) and there is some evidence to suggest other factors as stronger overall correlates of fatigue (e.g., depression, negative automatic thoughts; Aprin-Cribbie & Cribbie, 2007). Further, given the cross-sectional nature of the above studies, it is not possible to draw any conclusions about the direction of the association between perfectionism and fatigue.

### ***Clinical groups***

Three cross-sectional correlational studies exploring the relationship between fatigue and perfectionism in a clinical sample of CFS patients were identified. Brooks, Rimes and Chalder (2011) explored the role of negative perfectionism, lack of acceptance and depression in predicting fatigue among a sample of 259 CFS patients. Correlational analyses revealed a small but significant relationship between negative perfectionism and fatigue ( $r= .16$ ,  $p<.05$ ). In a stepwise regression, with fatigue as the dependent variable and DA and lack of acceptance as predictor variables, DA was found to be the only significant predictor. When regression analyses were run again, including depression scores, depression was found to be the only significant predictor of fatigue when DA and depression were entered.

Kempke, Van Houdenhove et al. (2011) utilised a structural equation modelling framework, to investigate whether positive or negative perfectionism were differentially associated with severity of depression and fatigue in a large group ( $N=192$ ) of CFS patients. Perfectionism was measured using the Dutch version of the Frost MPS, divided into positive (PS subscale) and negative (CM and DA subscale) factors. Correlational analyses revealed small to moderate correlations between negative perfectionism and fatigue ( $r=.22-.36$ ,  $p<.001$ ). Further, a model was supported in which negative (i.e., high levels of self-criticism and self-doubt) but not positive perfectionism (i.e., high personal standards) was significantly and positively related to severity of fatigue and depression. Moreover, the results

supported a full mediation model in which depression fully mediated the effect of negative perfectionism on fatigue.

Valero, Sáez-Francàs, Calvo, Alegre and Casas (2013), utilising a similar sample (N=299 CFS patients) and study design, investigated the relationship between negative perfectionism, fatigue and depression while also exploring the potential role of a fourth variable, neuroticism. Correlational analyses revealed significant positive correlations between all variables. The lowest effect observed was the moderate correlation between severity of fatigue and negative perfectionism ( $r = .39$ ,  $p < .01$ ), while the largest correlation was between severity of depression and fatigue ( $r = .65$ ,  $p < .01$ ). The authors failed to provide support for the findings of Kempke, Van Houdenhove et al. (2011), reporting that a model connecting negative perfectionism to fatigue through depression was not supported according to the indexes of goodness of fit. Rather, in the context of the multivariate analysis, a model was supported in which neuroticism predicted fatigue severity through depression.

It is important to note that there were two primary differences between these two studies that may have accounted for some of the discrepancies found. Firstly, the studies utilised different fatigue measures (see Table 2). Valero et al. (2013) measured the impact of fatigue on daily functioning whereas Kempke, Van Houdenhove et al. (2011) measured fatigue severity. Therefore, it may be that the two studies were not measuring equivalent constructs of fatigue, accounting for the difference in findings.

Secondly, as noted above, Valero et al. (2013) included neuroticism as an alternative explaining factor. Perfectionism and neuroticism are highly correlated constructs (e.g., Dunkley, Blankenstein, & Berg, 2012). It could be argued that perfectionism may well be reasonably integrated within the neuroticism construct, and thus in competition with the effects of neuroticism, the relationship between perfectionism and fatigue was not significant.

### *Summary*

Cross-sectional research supports a relationship between negative perfectionism and fatigue in CFS patients. Further, findings by Kempke, Van Houdenhove et al. (2011) suggest the role of depression as a potential mediator in this relationship, although this was not supported in a similar study by Valero et al. (2013). Valero et al. (2013) proposed that neuroticism may be a more consistent factor than negative perfectionism in the conceptualisation of CFS severity; further research would be needed to confirm this.

All three studies employed samples from tertiary care. Although this implies a rigorous diagnostic protocol, it may have biased the sample towards a more severe clinical profile making generalising findings difficult. Furthermore, although the two latter studies utilised more sophisticated methods of analysis in the form of structural equation modelling, the cross-sectional nature of the studies precludes the ability to make causal conclusions.

### **Case Control Studies**

#### ***CFS patients vs. healthy controls***

Four studies compared perfectionism levels between individuals with CFS and healthy controls. White and Schweitzer (2000) utilised a sample of 44 CFS patients and 44 healthy controls, matched on age and gender. Findings indicated that the CFS group reported higher levels than the controls on total and negative perfectionism (DA and CM). This finding was supported by Deary and Chalder (2010) who reported higher levels of negative perfectionism (CM, DA, PC), anxiety and depression in patients with CFS (N=27) compared to healthy controls (N=30).

Conversely, Blenkiron, Edwards and Lynch (1999) found that perfectionism scores were lower in their CFS sample (N=40), reflecting fewer perfectionistic traits than the control group (N=31), particularly on measures of OOP. The authors proposed that lower perfectionism scores among those with CFS may have reflected individuals' attempts to moderate their perfectionistic tendencies and standards to adjust to their condition. However, given that no measures of pre-morbid

perfectionism were taken it is not possible to confirm this. In the most recent study, Rimes, Papadopolous, Cleare and Chalder (2014) failed to find a difference in perfectionism scores (as measured using the CAPS; Flett et al., 1997) between their sample of 49 adolescents with CFS and 36 healthy controls.

### *Summary*

In summary, the evidence is mixed with regard to whether patients with CFS exhibit greater perfectionistic tendencies than their healthy counterparts. Given the limited number of studies it is difficult to draw any firm conclusions. All studies utilised small sample sizes, increasing the likelihood of sampling error i.e., chance or random error in the choice of a representative sample compared with the total population under consideration. In addition, differences in study design, such as the use of different questionnaires may have yielded inconsistent findings, making it difficult to compare and draw conclusions from these studies.

A major limitation in each of the above studies was the lack of direct assessment of pre-morbid perfectionism. As such, it cannot be certain whether patients with CFS were more or less perfectionistic prior to their diagnosis or whether their levels of perfectionism reflected a reaction to their ongoing fatigue. This methodological weakness could be addressed in future studies by utilising a prospective design.

All studies utilised healthy rather than illness control groups and three restricted their patient sample to predominately white female populations with a high degree of education. Although the latter demographics reflect the characteristics of many secondary and tertiary care CFS patients, these findings may not be representative of the CFS population in primary care or the community. It would be of value to investigate perfectionism in a population of newly diagnosed CFS patients; such an investigation may lead to a better understanding of the role of perfectionism in the development of the condition over time.

### ***Retrospective case-control***

Luyten, Houdenhove, Cosyns and Van den Broeck (2006) utilised a retrospective case-control design to investigate the relationship between premorbid and post-morbid perfectionism, fatigue and depression in a sample of 43 CFS patients and 80 student controls. In so doing the authors aimed to gain further clarity on the role of perfectionism in the development of CFS. The authors utilised a Flemish-Dutch version of the Frost MPS; a modified version of the Frost-MPS used to measure premorbid perfectionism (“pre-illness MPS-F”).

Results indicated that CFS patients scored significantly higher than students on both positive (PS and O) and negative (DA, CM) premorbid perfectionism. After illness onset, CFS patients continued to show significantly higher scores on both negative (DA) and positive (O) perfectionism subscales. However, scores on PS and CM were significantly lower, suggesting that the CFS patients lowered their personal standards and showed less concern over mistakes following illness onset. This finding appears in line with some previous research suggesting that patients with CFS may experience fewer perfectionistic beliefs post-diagnosis (e.g., Blenkiron et al., 1999).

Inherent in a retrospective study design are problems related to social desirability, inaccurate and selective recall. Further evidence for the hypothesis that perfectionism is a potential candidate influencing the onset or course of CFS must be more rigorously tested using prospective designs. Further, these findings need to be replicated in studies comparing CFS patients with community patients and other patient groups.

### ***CFS patients vs. patients with other chronic conditions***

Do individuals with CFS have higher levels of perfectionism than individuals with other chronic conditions? This question raises the issue of specificity: is there a special relationship between perfectionism and CFS or is this personality trait a factor in other types of chronic illness?

Two studies have explored this issue. Wood and Wessely (1999) explored whether specific personality traits and social attitudes characterised CFS patients. One

hundred and one CFS patients and 45 patients with rheumatoid arthritis took part in the study. No statistically significant differences were found between groups on personality measures, including perfectionism (as assessed using the Frost MPS). The stereotype of CFS patients as perfectionists was not supported when compared with patients suffering from another physically disabling illness.

In a recent study, Sirosis and Molnar (2014) compared levels of perfectionism across three patient groups (CFS, Irritable Bowel Syndrome and Fibromyalgia/arthritis) and a healthy control group. In contrast to the findings of Wood and Wessely (1999), negative perfectionism (as measured using the APS-R; Slaney et al., 2001) was found to be higher among the CFS group relative to the other chronic conditions and healthy controls. The authors took this finding to suggest the importance of negative perfectionism in CFS. It is important, however, to note that whereas the first study (Wood & Wessely, 1999) utilised clinical populations, the second study recruited through a population based survey in which participants' self-reported diagnosis. The lack of a medically-screened sample in the latter study may account for the difference in findings and may bring into question the validity of the findings.

### *Summary*

Only two studies to date have explored the issue of specificity, with conflicting results. These studies have varied in terms of the samples used, methods of recruitment and measures of perfectionism; as such no clear conclusions can be drawn. Further research, utilising a range of medically-screened clinical comparison groups, including individuals with other chronic medical health complaints as well as psychiatric samples, is required in order to elucidate this further.

## **Prospective studies**

### *Non-clinical prospective studies*

Two prospective studies were identified which explored the role of perfectionistic beliefs in the development of fatigue in non-clinical samples. The first study utilised a sample of undergraduate students while the other, a sample of academic employees. Dittner, Rimes and Thorpe (2011) investigated whether negative



perfectionism would serve as a vulnerability factor for the development of fatigue in the context of increased stress. Perfectionism was measured utilising two trait perfectionism dimensions: Conditional Acceptance (CA) and Perfectionist Striving (PS), derived from the Hewitt and Flett MPS. Fatigue was assessed using visual analogue scales (of both mental and physical fatigue) and the Chalder Fatigue Scale (Chalder et al., 1993). Students were asked to complete measures of perfectionism and fatigue both at the beginning of the academic year (T1) and again following a time of academic pressure, 16 weeks later (T2). Findings indicated that participants were significantly more fatigued at T2 than at T1. Negative perfectionism (i.e., CA) was correlated with all measures of fatigue at T1 ( $r=.12-.16$ ,  $p<.05$ ) and predicted subsequent levels of fatigue after controlling for T1 fatigue. Furthermore, positive perfectionism (i.e., PS) was found to be negatively correlated with fatigue in the cross-sectional analysis ( $r=-.13$ ,  $p<.01$ ).

Regression analyses were also carried out to investigate whether there was a correlation between T1 negative perfectionism and a range of variables hypothesised to mediate the relationship between negative perfectionism and fatigue (stress, depression, unhelpful academic behaviours, and health behaviours). The only significant correlation was between T1 negative perfectionism and T2 depression. Furthermore, mediation analyses revealed that depression mediated the relationship between negative perfectionism and subsequent physical fatigue.

In the second prospective investigation, Flaxman, Ménard, Bond and Kinman (2012) explored the impact of perfectionism on fatigue and well-being in a sample of 77 academic employees. Participants were divided into perfectionistic and non-perfectionistic groups, based on their scores on the DA subscale of the Frost MPS (MPS-DA; Frost et al., 1990). Fatigue was assessed using the Warr's (1990) Affective Well-being Scales (see Daniels, Brough, Guppy, Peters-Bean, & Weatherstone, 1997). Participants were asked to complete questionnaire measures 2 weeks prior to (T1), during (T2) and on two occasions after (T3; 2 weeks post-respite and T4; 5 weeks post-respite) a 4-day respite from work. Findings revealed that in post-respite working weeks, academics exhibiting negative perfectionism (i.e., DA) reported significantly higher levels of fatigue ( $r=.28-.40$ ,  $p<.05$ ). Further,

the relationship between negative perfectionism and fatigue was mediated through the tendency for perseverative thinking (e.g., worry and rumination) about work during respite itself.

### *Summary*

In summary, two non-clinical studies provide support for the role of negative perfectionism in predicting the development of fatigue symptomology. Further, like previous research (Kempke, Van Houdenhove et al., 2011; Macedo et al., 2015), findings support the role of depression and associated processes (e.g., perseverative negative thinking) as mediators in this relationship.

### *Clinical prospective studies*

To date, only two prospective studies have attempted to explore the relationship between perfectionistic beliefs and CFS using clinical samples. Moss-Morris, Spence and Hou (2011) explored whether psychological factors proposed in the cognitive behavioural model of CFS could predict the onset of chronic fatigue (fatigue at 3 months) and CFS (fatigue at 6 months) following an acute episode of glandular fever. Patients (N=246) who agreed to participate in the study completed a baseline questionnaire at the time of their acute infection (T1) which included a range of potential risk factors for CFS (including perfectionism, mood, perceived stress, somatisation, illness beliefs and behaviour). Patients were followed-up at 3 (T2) and 6 months (T3). Findings revealed that negative perfectionism (as measured using the negative subscale from the PANPS; Slade & Owens, 1998) was a risk factor for the development of CFS at 6 months follow-up. A number of other variables were also significant predictors at both 3 and 6 months (anxiety, depression, somatisation, negative illness beliefs and all-or-nothing behavioural patterns), suggesting the involvement of multiple factors in the development of fatigue (Wessely et al., 1998). Although an interesting finding, it is important to take into consideration that the above model was only tested in one 'at risk' sample (post-glandular fever CFS) therefore generalisability of these findings to the wider group remains to be determined. Furthermore, diagnosis of CFS was not reached through clinical assessment but was self-reported. Thus, these findings should be interpreted with some caution.

In a recent study, Kempke et al. (2013) investigated whether negative perfectionism (referred to in the study as self-critical perfectionism) could prospectively predict daily symptoms of fatigue in a sample of 99 CFS patients. Unlike previous research, this study employed a daily diary method procedure in which patients were asked to rate their average daily fatigue levels using a visual analogue scale (VAS). Results indicated that negative perfectionism (as measured using the DEQ) prospectively predicted fatigue levels over a 14-day period. This effect remained significant even when controlling for depression. Given this research utilised an already fatigued sample, insight into the role of perfectionism in the onset of fatigue is not provided; however this study does suggest that perfectionism may be associated with symptom exacerbation.

### *Summary*

There is currently minimal prospective research investigating the relationship between perfectionism and fatigue using clinical samples. To date, only one study Moss-Morris, Spence and Hou (2011) has investigated whether perfectionism may be a genuine risk factor for the development of CFS, despite this being the fundamental assumption of the cognitive-behavioural and psychodynamic models for the development of CFS. Further, the findings of this study indicate that although a contributory factor, perfectionism may be one of a number of variables important in the development of fatigue. This fits with a biopsychosocial model of CFS which indicates a multi-factorial etiology.

### **Treatment studies**

To date, research evidence supports the efficacy of CBT and graded exercise therapy (GET) in the treatment of CFS (see meta-analyses; Castell, Kazantzis, & Moss-Morris, 2011; Edmonds, McGuire, & Price, 2004; Malouff, Thorsteinsson, Rooke, Bhullar, & Schutte, 2008; Price, Mitchell, Tidy, & Hunot, 2008). Although a number of these studies (e.g., Chalder, Tong, & Deary, 2002; Sharpe et al., 1996) have purported to address negative perfectionism as part of the treatment, only one to date has explored change in perfectionism levels over the course of intervention. Brooks, Rimes and Chalder (2011) investigated the effectiveness of a short-term (12 week,

fortnightly) CBT intervention in reducing negative perfectionism and improving acceptance among a sample of 90 CFS patients. It was hypothesised that negative perfectionism (CM and DA) would reduce over the course of therapy. Outcome measures were completed at pre-, post and 3-months follow-up.

As predicted, findings indicated that CM was significantly lower at discharge and follow-up, and DA lower at discharge only. Scores on the PC and PE subscales did not change significantly after treatment. The authors argued that this was unsurprising given that CBT would be more focussed on addressing current high standards and evaluative concerns than on perceptions of parental standards.

Given that this change took place within the context of a non-randomised cohort study with no control group, it cannot be concluded that the intervention was necessarily responsible for the reduction in symptoms. Comparison with an untreated CFS group would be necessary to clarify whether change in perfectionism scores could have been due to natural course or engagement in treatment.

### **Perfectionism as a predictor of treatment outcome**

Lloyd, Chalder, Sallis and Rimes (2012) explored perfectionism as a predictor of outcome (specifically fatigue severity and school attendance) following a 6 session, telephone-based guided self-help CBT intervention for CFS in adolescent youths. Findings indicated that higher baseline levels of SOP and SPP (as measured using the CAPS; Flett et al., 1997) were significantly associated with increased odds of having an improved outcome for school attendance. Baseline perfectionism was not associated with post-intervention fatigue levels.

Table 1

*Summary of Non-Clinical Studies*

Study	Sample	Gender and Age	Perfectionism measure	Fatigue measure	Results
Aprin-Cribbie & Cribbie (2007)	307 undergraduate students	120 men, 187 women, Mean age= 19.7 (SD = 4.0)	Two sub-scales (SOP and SPP) from the MPS-H  Two subscales (social approval and perfectionism) from the DAS.	PFRS	Perfectionism significantly correlated with fatigue-related emotional distress ( $\beta = 0.13$ , $p < .05$ ) and cognitive difficulties ( $\beta = 0.18$ , $p < .05$ ).
Dittner, Rimes & Thorpe (2011)	436 undergraduate students	308 women, 128 men, Mean age = 20.4 (SD=5.3)	Two subscales (CA and PS) from the four factor analysis of the MPS-H	Visual analogue fatigue scales and the CFQ	Negative perfectionism (i.e., CA) was correlated with all measures of fatigue at T1 ( $r = .12-.16$ , $p < .05$ ) and predicted subsequent levels of fatigue after controlling for T1 fatigue. Positive perfectionism (i.e., PS) was found to be negatively correlated with fatigue ( $r = -.13$ , $p < .01$ ). Depression mediated the relationship between negative perfectionism and subsequent physical fatigue.
Flaxman, Menard, Kinman, & Bond (2012)	77 academic employees	49 women, 28 men, Mean age= 46 (SD =10)	DA subscale of the MPS-F	Fatigue subscale of the Warr's Affective Well-Being scales	Academics exhibiting negative perfectionism (i.e., DA) reported significantly higher levels of fatigue ( $r = .28-.40$ , $p < .05$ ) during post-respite working weeks. Further, the relationship between negative perfectionism and fatigue was mediated through the tendency for perseverative cognition about work during respite itself.

Study	Sample	Gender and Age	Perfectionism measure	Fatigue measure	Results
Macedo et al. (2009)	421 pregnant women	All women Mean age =29.8 (SD=4.5; range=19-44 years)	Two sub-scales (SOP and SPP) from the Portuguese version of the MPS-H	Fatigue subscale of the Portuguese version of the POMS	Small positive correlation between negative perfectionism (SPP) and fatigue symptoms ( $r = .23$ , $p<.001$ )
Macedo et al. (2015)	788 undergraduate students	572 women, 216 men Mean age = 20.3 (SD = 2.0; range = 17–25 years)	Portuguese versions of the MPS-F and the MPS-H	Fatigue-interia subscale of the POMS	Moderate correlation between negative perfectionism (i.e., EC) and increased fatigue ( $r = .44$ , $p<.01$ ). Perfectionism scores (EC and PS) accounted for additional variance in fatigue over perceived stress and social support. Repetitive negative thinking mediated relationship between fatigue and perfectionism.
Magnusson, Nias, & White (1996)	121 nurses	All women Median age = 25 (range = 21-56 years)	MPS-F	Visual analogue scale of symptomatic fatigue	Significant small to moderate correlations between negative perfectionism and increased mental and physical fatigue ( $r = .19-.30$ , $p<.05$ ),
Saboonchi & Lundh (2003)	184 healthy adults	102 women, 80 men Mean age = 37 (SD = 7.4 men, SD = 8.1 women)	MPS-H	Tension/Fatigue subscale of the SEEI	Positive and negative perfectionism showed small but significant positive correlations ( $r = .18-.20$ , $p<.05$ ) with self-reported somatic complaints, specifically the 'Tension/Fatigue' subscale.

*Note.* MPS-F = Multi-dimensional perfectionism scale-Frost; MPS-H = Multi-dimensional perfectionism scale – Hewitt & Flett; SOP = Self Orientated Perfectionism; SPP = Self Prescribed Perfectionism; DAS = Dysfunctional Attitudes Scale; PFRS = Profile of Fatigue-Related Symptoms; CFQ = Chronic Fatigue Questionnaire; CA = Conditional Acceptance; PS = Perfectionist Striving; DA = Doubts about Actions; POMS = Profile of Mood States; SEEI = Somatic and Emotional Experiencing Inventory.

Table 2

*Summary of Clinical Studies*

<b>Study</b>	<b>Sample</b>	<b>Gender and Age</b>	<b>Perfectionism measure</b>	<b>Fatigue measure</b>	<b>Results</b>
Blenkiron, Edwards, & Lynch (1999)	40 CFS patients 31 healthy controls	CFS group = 24 women, 16 men, Mean age = 49 (range 21-66 years) Healthy control group = 18 women, 13 men, Mean age = 40 (range 21-68 years)	MPS-H	CFQ	Perfectionism scores were lower in the CFS sample (N=40), reflecting fewer perfectionistic traits than the control group, particularly on measures of others orientated perfectionism (OOP).
Brooks, Rimes, & Chalder (2011)	259 CFS patients (of these 90 CFS patients underwent cognitive behavioural therapy (CBT) and completed all measures)	195 women, 64 men, Mean age = 39.2 years (SD=11.9; range = 18–80 years).	Four negative subscales (CM, DA, PE and PC) from the MPS-F	CFQ	Small but significant relationship between negative perfectionism (specifically DA) and fatigue ( $r = .16$ , $p < .05$ ). Following 6 sessions of CBT, CM was significantly lower at discharge and follow-up, and DA lower at discharge only. Scores on the PC and PE subscales did not change significantly after treatment.
Deary & Chalder (2008)	27 CFS patients 30 healthy controls	All women CFS group = Mean age = 41.2 (SD = 8.9), Healthy control group = Mean age = 37.7 (SD = 7.8).	MPS-F	CFQ	CFS group reported significantly higher levels than controls on negative perfectionism (CM, DA, PC).

Study	Sample	Gender and Age	Perfectionism measure	Fatigue measure	Results
Kempke, Van Houdenhove et al.(2011)	192 CFS patients	164 women, 28 men Mean age = 40.2 years (S.D.=9.4, range 19–66 years)	Two negative subscales (DA, CM) and one positive subscale (PS) from the MPS-F	The Dutch version of the CIS-20	Correlational analyses revealed small to moderate correlations between negative perfectionism and fatigue ( $r=.22-.36$ , $p<.001$ ). The results supported a full mediation model in which depression fully mediated the effect of negative perfectionism on fatigue.
Kempke et al. (2013)	99 CFS patients	92 women, 7 men, Mean age = 41.7 years (S.D.=8.7, range 18–59 years)	Self-critical perfectionism subscale of the DEQ	Visual analogue scales of fatigue severity	Negative perfectionism prospectively predicted fatigue levels over a 14-day period. This effect remained significant even when controlling for depression ( $\beta = 3.37$ , $p<.05$ ).
Lloyd, Chalder, Sallis, & Rimes (2012)	63 adolescents with CFS	14 girls, 9 boys, Median age = 15 (range 14.0-16.5 years)	CAPS	CFQ	A significant decrease in fatigue was found between pre-treatment and 6 month follow-up. A significant increase in school attendance was found between pre-treatment and 6 month follow-up. Univariate logistic regression found baseline perfectionism to be associated with improved school attendance at six-month follow-up.
Luyten, Van Houdenhove, Cosyns, & Van den Broeck. (2006)	43 CFS patients and 80 student controls	CFS group = 37 women, 6 men, Mean age = 39.1. Students = 67 women, 13 men, Mean age 21.4.	MPS-F and modified pre-illness MPS	The Dutch version of the CIS-20	Results indicated that CFS patients scored and negative premorbid perfectionism. After illness onset, CFS patients continued to show significantly higher scores on both negative and positive perfectionism subscales.



Study	Sample	Gender and Age	Perfectionism measure	Fatigue measure	Results
Moss-Morris, Spence, & Hou (2011)	246 with diagnosis of glandular fever	152 women, 94 men, Mean age = 22.8 (S.D =8.3)	The negative subscale from the PANPS	Centers for Disease Control or British criteria were used to identify CFS cases.	9.4% met the criteria for Chronic Fatigue (CF) at 3 months and 7.8% met the criteria for CFS at 6 months. Perfectionism was associated with new-onset CFS at 6 months but not at 3 months.
Rimes, Papadopolous, Cleare, & Chalder (2014)	49 adolescents with CFS, 36 healthy adolescent controls	CFS group = 31 girls, 18 boys, Mean age = 14.9 (SD= 1.7) HC group = 21 girls, 15 boys, Mean age =15.0 (SD = 1.7)	CAPS	CFQ	No significant difference in perfectionism scores between the two groups.
Sirosis & Molnar (2014)	79 CFS, 85 IBS, 70 FM/arthritis) and 94 healthy controls	CFS group = Mean age 32.8 (range 30.5-35.0); IBS group= Mean age 37.5 (range 35.4-39.7 years); FM/arthritis group = Mean age 38.9 (range 36.1-41.6 years); HC group = Mean age 31.1 (range 9.4-32.7 years)	APS-R	No self-report fatigue scales used	Perfectionism was found to be higher among the CFS group relative to the other chronic conditions and healthy controls.

Study	Sample	Gender and Age	Perfectionism measure	Fatigue measure	Results
Valero Saez-Francas, Calvo, Alegre, & Casas (2013)	229 CFS patients	209 women, 20 men, Mean age = 48.21 years (SD = 8.93, range 22–73 years)	Two negative subscales (DA, CM) and one positive subscale (PS) from the MPS-F	U-FIS	Moderate correlation between severity of fatigue and negative perfectionism ( $r = .39$ , $p < .01$ ). A model connecting negative perfectionism to fatigue through depression was not supported. Rather, a model was supported in which neuroticism predicted fatigue severity through depression.
White & Schweitzer (2000)	44 CFS patients and 44 healthy controls	12 men, 32 women, Mean age = 43.27 (range = 18–67 years) (groups did not differ sig. on age or gender)	MPS-F	No self-report fatigue scales used	CFS group reported significantly higher levels than the controls on total and negative perfectionism (DA and CM)
Wood & Wessley (1999)	101 CFS patients and 45 patients with rheumatoid arthritis (RA)	CFS Group = 40 men, 61 women, Mean age = 36.6 (SD = 10.5) RA Group = 9 men, 36 women, Mean age = 42.2 (SD = 9.6)	MPS-F	No self-report fatigue scales used	No statistically significant differences in perfectionism were found between the two groups.

*Note.* MPS-F = Multi-dimensional perfectionism scale-Frost; MPS-H = Multi-dimensional perfectionism scale – Hewitt & Flett; OOP = Others Orientated Perfectionism; CFQ = Chronic Fatigue Questionnaire; DA = Doubts about Actions; CM = Concerns about Mistakes; PS = Parental Standards; PE = Parental Expectations; PC = Parental Criticism; APS-R = Almost Perfect Scale – Revised; PANPS = Positive and Negative Perfectionism Scale; U-FIS = Uni-

dimensional Fatigue Impact Scale; CIS-20 = Checklist Individual Strength-20; DEQ = Depressive Experiences Questionnaire; CAPS = Child and Adolescent Perfectionism Scale; IBS = Irritable Bowel Syndrome; FM = Fibromyalgia

## Discussion

This review provides a critical overview and synthesis of findings published in studies pertaining to the relationship between perfectionism and fatigue. Overall, the majority of studies provide support for the cognitive and psychodynamic models of CFS. Findings from cross-sectional research indicate that perfectionism is significantly correlated with fatigue, typically with small to moderate associations ( $r=.12-.44$ ). More specifically, findings indicate that negative aspects of perfectionism (e.g., CM, DA and SPP) and in some cases positive perfectionism (e.g., PS, SOP) are positively correlated with fatigue symptomology. This suggests that fatigue may be one context in which 'positive' perfectionism may become maladaptive. Positive perfectionism reflects the active striving for high standards and achievement: in the context of chronic illness, such traits may lead to over-striving and the perpetuation of symptoms.

Case-control studies comparing perfectionism in CFS patients with healthy participants or illness control groups have revealed less consistent findings, with some indicating elevated levels of negative perfectionism among CFS patients, while others reported lower levels of perfectionism or no significant differences between groups. The reason for this variability is unclear but contributing factors are likely to include differences in sample size and composition as well differences in measures of perfectionism and fatigue.

Only four prospective studies have explored the role of perfectionism in the development of fatigue. Their results are consistent with the suggestion that perfectionism may be a potential risk factor for fatigue, although it is likely to be one of several contributory factors. One retrospective study found that people with CFS report higher levels of perfectionism premorbidly. This may suggest that once the condition has developed, individuals are either unable to maintain their previous high standards or choose to modify them.

In recent years, researchers have begun using more complex models of analysis to explore mediating factors in the relationship between perfectionism and fatigue.

These findings indicate the role of depression as a significant correlate of fatigue and where the study design has allowed, depression and repetitive negative thinking have been revealed as potential mediators in the relationship between perfectionism and fatigue. These findings are consistent with previous research that has found negative perfectionism to be associated with depression (Hewitt & Flett, 1993) and repetitive negative thinking (Burns & Fedewa, 2005; Frost et al., 1997; Kobori & Tanno, 2005) as well as evidence that psychological distress/depression is associated with increased fatigue (Pawlikowska et al., 1994; van Geelen et al., 2007).

One preliminary study has explored the impact of CBT for perfectionism on fatigue symptomology, indicating positive results. Further, one study investigated the impact of perfectionism as a predictor of outcome (specifically fatigue severity and school attendance). Contrary to prediction, perfectionism was not found to predict post-intervention fatigue and was associated with improved school attendance. This finding is in contrast to other studies: for example in eating disorders, results have shown perfectionism to be associated with poorer outcome (Bizeul, Sadowsky, & Rigaud, 2001; Sutandar-Pinnock, Blake Woodside, Carter, Olmsted, & Kaplan, 2003).

### **Methodological issues**

The majority of studies utilised a cross-sectional design which constrains inferences as to a causal role for perfectionism in the development of fatigue. Indeed, this may reflect the embryonic nature of the research field in this area, with most studies conducted within the last 10 years. A prospective design was employed in only a limited number of cases: such designs are prerequisite for determining if perfectionism is a true risk factor for fatigue.

Although the majority of studies employed one of the recognised perfectionism scales, some authors chose to exclude some subscales or conduct analyses using an aggregate score for perfectionism. While this is often needed due to administrative constraints, it creates problems when comparing results. Further, using single subscales as a measure of negative or positive perfectionism may call into question the reliability of the findings. Flaxman et al. (2012) reported that the DA-subscale of

the Frost MPS (used as their single measure of negative perfectionism) demonstrated surprisingly low internal consistency ( $\alpha = .65$ ). One resolution of this issue would be to develop shortened versions of the scales.

This review highlighted a lack of consistency between measures of fatigue. Indeed, across the twenty studies, eleven different measures of fatigue were used. Although findings were fairly consistent regardless of the measure employed, it is important to make note of the quality of these assessment tools. Some studies utilised validated measures of fatigue whereas others used visual analogue scales or subscales within more general measures of mood and somatic complaints which have yet to be validated in larger scale studies. Moreover, as with measures of perfectionism, the variation in measures of fatigue means that it is difficult to make direct comparisons between studies. Scales differed in focus, with some measuring fatigue severity only, whereas others looked at the nature of fatigue and the impact on functioning. Furthermore, non-clinical studies relied exclusively on self-report measures of fatigue and this may have inflated observed relationships. Future studies would benefit from alternative collection approaches, such as multiple informant measures or physiological measures of fatigue.

Non-clinical studies utilised a range of adult samples including female nursing staff, academic employees, undergraduate students, and pregnant mothers. Conversely, studies utilising CFS patients tended to be relatively homogenous, with a propensity towards Caucasian female patients accessing secondary or tertiary care services. Future studies, utilising samples of male participants as well as newly diagnosed CFS patients and general population samples would be useful in broadening our understanding of the relationship between perfectionism and fatigue.

It should be noted that two of the reviewed studies comprised of adolescent samples (Lloyd, Chalder, Sallis, & Rimes, 2012; Rimes, Papadopolous, Cleare, & Chalder, 2014). Given that adolescents will be in a different developmental phase to the adult population, it is plausible that there may be different contributory factors when looking at the relationship between perfectionism and fatigue (Fry & Martin, 1996).

Caution should therefore be taken when combining the findings from both adolescent and adult samples.

Only six studies employed control groups: four utilised healthy individuals, and two utilised individuals experiencing chronic illness. As such, it is not clear whether the results of these studies are specific to CFS or may be true for other chronic illnesses or the general population. Further, most of these studies had small sample sizes, reducing the statistical power to identify true differences and increasing the likelihood of sampling error. Additional understanding as to the specific role of perfectionism in the development of CFS will require the inclusion of other clinical comparison groups including clinical and population based samples and larger sample sizes.

### **Future directions for perfectionism and CFS research**

With the previous suggestions for improvement withstanding, a number of future directions for perfectionism and CFS research are worthy of note. Further research is necessary to determine whether perfectionism accounts for unique variance in CFS over and above other predictive factors, whether perfectionism interacts with other variables to explain CFS and to identify the mechanism(s) underpinning the link between perfectionism and CFS.

This review highlighted the role of depression and repetitive negative thinking as mediators in the relationship between perfectionism and fatigue. However, further research is needed to determine the mechanisms that may underpin this relationship. For example, it could be hypothesised that repetitive negative thinking regarding the discrepancies between the individual's current and premorbid levels of performance lead to a reduction in self-esteem and subsequent depression. There is some evidence to suggest the role of self-esteem as a mediator in the relationship between perfectionism and depression in individuals with CFS (Kempke, Luyten et al., 2011). Further research on this topic is needed.

Further, there is evidence to suggest that repetitive negative thinking leads to sustained stress-related physiological and emotional arousal (Brosschot, Gerin, & Thayer, 2006). It could be hypothesised that prolonged repetitive negative thought regarding one's condition and its implications may cause a 'switch' in the stress system from a state of over-drive to under-drive, leading to the development of fatigue. Exploring this mechanism in future research is a noteworthy proposal.

Finally, despite studies exploring the relationship between perfectionism and fatigue, only one so far has explored the impact of psychological intervention for perfectionism among CFS patients (Brooks, Rimes, & Chalder, 2011). Given that the research to date highlights perfectionism as a potential risk and maintenance factor in fatigue, it makes sense that treatment studies should be further explored. Future treatment research should focus on tailoring interventions to directly address the factors proposed to contribute to the development and maintenance of perfectionism, such as depression and repetitive negative thought. Further, research should focus on utilising more robust methodology (e.g., RCT's) to bring about new insights into the treatment of perfectionism, and the impact of this on fatigue.

### **Limitations of the review**

There were several limitations regarding this review. First, potential eligible studies were assessed for inclusion by the first author only. In addition, no measures of methodological quality were taken. Furthermore, there may have been a publication bias, favouring reports of significant findings and working against failures to replicate.

### **Clinical implications**

This review indicates that perfectionism is related to fatigue, in line with both cognitive and psychodynamic models of CFS. The application of psychological interventions, such as CBT for the remediation of perfectionism among CFS patients therefore warrants further research. Furthermore, clinicians may benefit from paying greater attention to depression and repetitive negative thinking, as these variables



have been shown to have a potential role in mediating the relationship between perfectionism and fatigue.

Although these findings are encouraging, caution is needed. Research exploring the role of perfectionism in the development and maintenance of fatigue is currently in its infancy. Further research seeking to replicate findings and to conduct prospective and experimental investigations is needed if we are to determine more clearly the potency of perfectionism, mechanisms of action and the causal relations. Further, research is needed to explore the relationship between fatigue and perfectionism across genders, ages and a range of clinical and non-clinical samples.

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## **Service Improvement Project**

### **A qualitative analysis of the information needs of parents of children with Cystic Fibrosis prior to first admission**

Vera Christina Fixter

Doctoral Programme in Clinical Psychology, Department of Psychology, University  
of Bath, Claverton Down, Bath, BA2 7AY, Tel: 01225 385506, Email:  
[vch23@bath.ac.uk](mailto:vch23@bath.ac.uk)

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Dr Jo Daniels and Dr Catherine Butler

External Supervisor:  
Dr Samantha Phillips

**Proposed Journal:** Journal of Cystic Fibrosis, a journal devoted to promoting the research and treatment of cystic fibrosis. To this end the journal publishes original articles, editorials, case reports, relevant to cystic fibrosis (see Appendix B for authors guidelines).

## Abstract

**Background:** Hospitalisation can be stressful for patients and their families. Pre-hospitalisation information is crucial in establishing a good basis for patient satisfaction and cooperation. This qualitative study explored whether parents of children with Cystic Fibrosis, admitted to a UK Children's Hospital, were adequately prepared for their child's admission. **Methods:** Data were collected from twelve parents whose children had been admitted within the last two years for routine intravenous antibiotic treatment. Semi-structured interviews were analysed using thematic analysis. **Results:** Four themes emerged from the analysis: the admission, the ward as a challenging environment, changes in the parent-professional relationship and the parental role in medical care. Parents reported feeling unprepared for their child's admission; the need to receive information addressing the medical, practical *and* psychosocial aspects of admission was emphasised. Findings highlighted the adverse effects of inadequate information on the hospital experience. **Conclusions:** Provision of adequate preparatory information is essential in reducing parental stress, influencing how future experiences are appraised and managed. Effective parent-professional communication and opportunities to participate in care will improve parental satisfaction.

**Keywords:** Cystic Fibrosis; Information needs; Parents; Intravenous antibiotics

## **Introduction**

Cystic Fibrosis (CF) is the most common, life-limiting, recessively inherited disease in the UK, affecting 1 in 2500 live births (Cystic Fibrosis Trust, 2011). Significant advances in medical science have resulted in improved survival rates (Elborn, 1998); however, there is presently no cure for CF and the current average life expectancy is 36.6 years (UK Cystic Fibrosis Registry, 2013).

Patients with CF are required to complete rigorous treatment regimens comprising of daily physiotherapy, medication and nutritional monitoring (Eiser, Zoritch, Hiller, Havermans, & Billig, 1995). During childhood and early adolescence, parents play an integral role in delivering care and facilitating treatment adherence within the home environment (Eiser et al., 1995; Modi, Marciel, Slater, Drotar, & Quittner, 2008). In some instances, hospitalisation for more intensive treatment is required (Mattsson, 1972). Many children with CF are admitted to hospital to undergo a course of intravenous (IV) antibiotics (lasting 2-3 weeks), in order to manage pulmonary exacerbations brought on by ongoing infection (Cystic Fibrosis Trust, 2009).

It is well recognised that hospitalisation is a highly stressful experience both for patients and their families (Commodari, 2010; Franck, Mcquillan, Wray, Grocott, & Goldman, 2010; Litke, Pikulska, & Wegner, 2012). Parents are required to familiarise themselves with new settings, routines, negotiate new roles in care and manage anxieties regarding their child's treatment (Verwey, 2008). For parents of children with CF, these uncertainties are likely to be especially challenging, given their central role in the day-to-day management of their child's condition (Darbyshire, 1992). There may be added stress due to in-hospital segregation measures; in place to reduce the possibility of cross-infection (Festini et al., 2006; Griffiths, Carzino, Armstrong, & Robinson, 2004). Evidence indicates that in-hospital segregation is associated with adverse psychosocial outcomes, including feelings of isolation and perceived lack of social support (Duff, 2001; Griffiths et al., 2004; Russo, Donnelly, & Reid, 2006).

High parental distress has been identified as a barrier to effective participation in child care and can adversely affect the hospitalised child both during (Power & Franck, 2008) and after admission (Alisic, Jongmans, van Wesel, & Kleber, 2011; Dunn et al., 2012; Kassam-Adams, Fleisher, & Winston, 2009; Nugent, Ostrowski, Christopher, & Delahanty, 2007). It is becoming increasingly recognised that informing and preparing parents of what to expect during their child's hospitalisation is crucial in reducing distress and enabling parents to maintain a key role in care (Commodari, 2010).

The National Service Framework for Children, Young People and Maternity Services (NSF CYPMS; Department of Health, 2003) has identified this need and has set out standards of care highlighting the importance of providing “accurate information [regarding hospitalisation] that is valid, relevant, up-to-date [and] timely” and doing so “utilising a range of communication methods so that information may be made available regarding specific conditions, medicines and procedures” (Department of Health, 2003, p. 16).

Research has shown that preparatory programmes such as the conveyance of detailed information in person, via leaflet or DVD have the potential to improve the hospitalisation experience for both patients and their families (Buckley & Savage, 2010; Schmidt, 1990; Shirley, Thompson, Kenward, & Johnston, 1998; Smith & Callery, 2005)

### **Service Context**

The CF team at the Bristol Royal Hospital for Children (BRHC) have identified a need for formal preparation for parents of children with CF prior to their child's inpatient hospital admission for IV antibiotics. This need was identified during a team discussion about the inpatient experience. Currently individuals are directed to online materials (provided through the University Hospital's Bristol Website) which offer generic practical advice, without reference to more specific aspects addressing medical, psychological and social factors. Given the stress associated with child hospitalisation, such resources may be insufficient to meet their needs.

### **Questions to be addressed**

- Do parents feel adequately prepared for their child's initial inpatient hospital admission?
- If not, how can the Bristol CF service better meet the needs of these parents, addressing the requirements set out by the NSF CYPMS (Department of Health, 2003)?

### **Method**

#### **Design**

A qualitative design was employed, through which data generated from semi-structured interviews were analysed using inductive thematic analysis (Braun & Clarke, 2006). Thematic analysis was chosen as the most appropriate qualitative method as it is a highly flexible approach that can be used across a range of epistemologies and research questions. Thematic analysis provides a reflective approach that allows researchers to capture the richness and in-depth nature of participants' experiences and allows for the generation of general themes across the data set.

#### **Participants and recruitment**

The team's Clinical Psychologist attempted to contact twelve parent couples for interview. Parents had been identified by the team's Senior Nurse and Physiotherapist. Parents were eligible for participation if (i) they had a child who had experienced their first inpatient hospital admission (or first inpatient hospital admission since infancy) within the last two years and (ii) the admission had been related to the delivery of scheduled IV antibiotics. Parents were excluded from the study if their child's admission was for diagnosis or an emergency procedure. Eligibility criteria were developed through discussion with the CF team.

Ten of the twelve parent couples were reached by telephone. Three attempts were made to contact the remaining two couples; however this was unsuccessful. Of the ten parent couples successfully contacted, all agreed to take part. Parents were sent



an invitation letter, information sheet and written consent form. They were invited to return the signed consent forms either by post or on attendance at the CF outpatient clinic. Once consent had been obtained, the researcher contacted each parent couple via telephone to arrange a face-to-face interview. The option of conducting the interview either at the outpatient clinic or in the parents' home was provided; all requested the latter.

On the day of the interview, only the mother of each parent couple was available in all but two cases with the primary reason given for absence being work commitments. In instances where both parents were available, a joint interview was arranged. Parents ranged in age from 35 to 70 years ( $M = 45.2$ ,  $SD = 9.8$ ), self-identified ethnicity was as follows: 11 White British and one Asian British. Children ranged in age from 2 to 14 years ( $M = 8.1$ ,  $SD = 4.1$ ). Ethical approval was obtained from the University of Bath Psychology Ethics Committee and the Research and Development department of the University Hospitals Bristol NHS Foundation Trust.

### **Semi-structured interviews**

Semi-structured interviews took place with each parent (or parent couple) who consented. The questions (see Table 1) that formed the topic guide were developed iteratively through discussion with the CF Clinical Psychologist and staff team in order to elicit information related to the research question. The purpose of the semi-structured interview was to systematically collect information from parents by asking uniform questions, while offering the flexibility for parents to provide additional relevant information and allow the interviewer to ask clarifying questions. Interviews were conducted by the first author. Interviews were audio-recorded and each lasted between 45 and 75 minutes.

Table 1

*Semi-structured interview questions*

- Remembering back to your child's most recent hospital stay, do you feel that you were adequately prepared for what to expect, both from a practical and emotional perspective?
  - If so, what information/advice did you find helpful?
  - If not, what information and/or support do you think would have been helpful?
- What effect did this preparation (or lack of) have on the admission experience?
- If we were to develop materials that would assist parents in preparing for their child's first hospital stay, what information do you think would be helpful to include, from a medical, practical, social and psychological perspective?

**Data Analysis**

The interviews were transcribed verbatim and analysed using Braun and Clarke's (2006) six-phase guide to thematic analysis. The first author read the transcripts repeatedly to ensure familiarisation with the data. Initial ideas were noted down and the data were then coded. Data with the same codes were collated and sorted into identifiable themes and subthemes. Themes were then refined through an iterative process whereby themes generated were compared back to the original text and their appropriateness and resonance in relation to the research question were reviewed. To ensure rigor, a 'paper trail' as suggested by Yardley (2008) was kept to identify how themes had developed over time.

To promote reliability of the analysis, the themes were verified by the second author, an experienced clinical psychologist and researcher within the area of clinical health psychology. The second author was provided with a sample of four interview transcripts and progressed through the step-by-step analysis process along with the

first author. Once both authors had coded and analysed the interviews, they met to discuss their findings and reach a consensus regarding the thematic structure. Finally, the third author, who had expertise within the area of CF, was asked to review the thematic map and codes as a final credibility check.

### **Quality Control**

There is no definitive set of guidelines for determining reliability and validity of qualitative research; however a range of guidelines do exist in the literature (e.g., Mays & Pope, 2000; Yardley, 2008). Elliot, Fischer, and Rennie (2001) provide a useful set of guidelines which intend to characterise the appropriate considerations involved in the conduct and publishability of qualitative research. These specific guidelines include: situating the sample (placing the sample in context including relevant descriptive data), grounding in examples (providing examples of primary data to illustrate themes), providing credibility checks (using methods to check the credibility of categories or themes such as the inclusion of multiple analysts or an auditor) and ensuring coherence (achieving coherence and integration while preserving nuances in the data). These considerations were addressed within the current research.

### **Results**

Four themes emerged from the analysis: the admission, the ward as a challenging environment, changes in the parent-professional relationship and the parental role in medical care. These themes describe the parents' 'journey' from the clinic to the hospital ward and the associated challenges that shaped their perceptions of the hospital experience. Pseudonyms have been used to preserve parent anonymity. See Table 2 below for participant quotes.<sup>1</sup>

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<sup>1</sup> Quotes reported within the Table as per the Journal of Cystic Fibrosis formatting guidelines

Table 2

*Participant quotes*

<b>Quote no. (participant)</b>	<b>Quote</b>
1 (1)	"I don't think we were prepared at all. We just were told she needed to go in. It was a situation where she had a couple of cough swabs done – literally I was scrambling to pack things like items of clothing, her medication, and just be prepared for myself to be there two weeks."
2 (2)	"It was all a bit last minute; we didn't know what was happening"
3 (3)	"It happened quite quickly, for me that was good as I don't want to mull things over too long"
4 (10)	"It was probably better in some ways because your mind isn't as anxious, and your mind isn't fully on it, so you can just deal with it"
5 (4)	"I felt quite sort of overwhelmed by it and the result was that I was very keen to put it off, which was not a good thing"
6 (6)	"Naturally you are going to push something like that away, you are not going to want to think about a hospital admission"
7 (4)	"She may have given me information that I wasn't able to take in at the time because we'd just come out of an appointment where we'd learned she was going into hospital"
8 (2)	"They did not really say what to bring or what to expect, they just said you need to bring her medication; that was it really....I felt like I was going in completely blind"
9 (5)	"I really felt that the psychological aspects of the admission were overlooked, they were not really discussed"
10 (6)	"The nurse explained a little of what to expect but this was mainly medical and practical information.... there was nothing about how we would feel emotionally"
11 (2)	"We did not know that one of the antibiotics could cause hearing loss. We thought, 'This is something else to worry about; they have not told us about this'. We felt we had no control over the situation."
12 (3)	"It would have been nice to have known what they were looking for and what it meant if they found 'secretions'...it would have helped me feel a bit more in control as I had not been through it before"

- 13 (5) "I guess the emotional preparation is important: being aware of how you are going to feel. It is full of anxiety really: if I went back, those first couple of days...fear not just for you but for your child"
- 14 (7) "It is hard for parents, especially when it's their child's first admission. I think helping parents see that what they are experiencing is normal would be really helpful"
- 15 (1) "There's no set time... ..it is very fluid, and you do end up waiting around"
- 16 (8) "The nurses and consultants are coming in, administering medication; you can't conform to routine"
- 17 (3) "We were lucky, we weren't on the ward but in our own room so had some privacy"
- 18 (3) "It is nice because you have your own room, but at the same time you're a bit isolated. I found that having a young child this was particularly the case as you have to be with them all the time"
- 19 (6) "[the nurses were] doing observations during the night and the lights were on so it was difficult to feel settled or that you had privacy in that room. One of the main things was that there was no let-up...it just felt 24/7"
- 20 (1) "It can be difficult to sleep. It's quite light, even when the lights go out...because you can hear stuff going on outside. If you don't sleep well, you don't function well"
- 21 (4) "There is the case that you meet parents of older children with CF...that was quite scary because I think we all hope treatments for CF are going to change radically over the next 10 years but at the same time you realise that you are in the same boat as people in a really really difficult situation and that can be quite alarming"
- 22 (6) "Once you have obviously overcome the shock and are coming around to the practicalities of CF, I think it would be useful to have a light hearted, informal visit to a ward, which I think would manage the fear and help you know what is coming"
- 23 (11) "I think maybe perhaps at the time they could have offered us... a walk around the ward to see what it was going to be like"
- 24 (7) "I'm so used to seeing my team, the Cystic Fibrosis team, and when we went in there I thought, 'Why are they not visiting today?'...It was very difficult because they provide so much support both medically and emotionally for both you and the kids and you don't really see them"
- 25 (5) "You think 'where are the people from the CF team, they are not

here'....you just want them to say, 'Hi [parent], how are you doing?'"

- 26 (8) "The community team are absolutely fantastic. It's almost like most of them have become members of the family"
- 27 (2) "I felt we were ignored to a certain degree. I know it's a patient to them but she's my daughter, I wanted to know she was ok"
- 28 (2) "They patched her up and nothing further was explained – we were not told what the next steps would be or when we would get the results"
- 29 (4) "I felt there was a slight tendency for staff to regard as routine what is actually an enormous upheaval for a family, particularly when you don't know the ropes"
- 30 (1) "When you arrive on the ward you expect to see the same physiotherapists, nurses and doctors that you see in clinic. To be confronted with a different team is a bit of a shock. I feel it is important for parents to know this so that they can prepare themselves and adjust their expectations accordingly"
- 31 (11) "I like to know because I think I like to maintain as much control as possible. When you're the parent of a child with CF you get used to taking an active role in their care"
- 32 (4) "You get used to being somebody who's part of the team looking after them and you don't really want to relinquish that when you go into hospital or feel like you have to because you are used to being the principal carer in a way"
- 33 (2) "Medication and physio was taken out of our hands. I felt like, 'I am her mum: I should be doing these things'. To be running on someone else's timescales was so annoying"
- 34 (12) "It can be frustrating when you feel the drugs have not been given how you would like"
- 35 (4) "There is a difficulty as a mother when your child goes into hospital...your relationship to your child is altered because suddenly you defer to the medical staff. I always feel a little bit hopeless and stupid when I am in hospital with my child"
- 36 (3) "I guess you get used to your own routine and helping your child administer their medications but then it gets taken out of your hands, you feel a bit useless"
- 37 (9) "I felt I wasn't in control and I think some of the things that I have done have brought back that control a little bit. Just making sure that I felt that I understood everything that was going on, and having people around me that I could trust and rely on and speak to

- about how I felt”
- 38 (4) “The advantage of having involvement in care is that after a few days we were giving the IV’s ourselves, just being watched by the nurses. We felt a cohesion to the team rather than just being a lump sitting there in the corner, regretting that our child was in hospital and not being able to do anything to make it better”
- 39 (10) “At the end of the day you’re in their hands: you go with what they want”
- 40 (4) “I think as parents...you regard it as a very long-term commitment to their health so you want to be as knowledgeable and involved as possible. The worst thing is being half involved and half knowledgeable”
- 

### **Theme 1. The admission**

In all cases, admissions took place within the context of routine symptom monitoring. This meant that the consulting CF physician made a decision, following necessary tests and observations, that a hospital admission for IV antibiotics was required.

#### *Suddenness of admission*

All parents described a relatively short period of time (i.e., a few days) between being informed of the possibility of admission and entering hospital. As a result, the admission was perceived as “last minute”, leaving little time to prepare for the hospital stay (Quotes 1 and 2, Table 2).

For two parents, the lack of time to prepare was positively received as it meant that they had little time to think things through, reducing anticipatory anxiety (Quotes 3 and 4, Table 2). For some, this perceived suddenness led to feelings of “shock” and a desire to deny the prospect of admission (Quotes 5 and 6, Table 2). For one parent, the news that her daughter was to be admitted was perceived as altogether “overwhelming”, affecting her ability to retain important information about the admission (Quote 7, Table 2).

### *‘Going in blind’*

Although the shock of admission may have impacted upon their ability to take on board what was said, parents unanimously reported that they received minimal preparatory information. For one parent, it felt as if she was “going in completely blind” (Quote 8, Table 2).

Parents noted that information provided was primarily medical and practical in nature with no exploration of the psychosocial implications (Quotes 9 and 10, Table 2). Some parents highlighted that although medical procedures were broached; information regarding outcomes, associated risks and possible side effects of the medication were not discussed, leaving them feeling out of control of their child’s long-term well-being (Quotes 11 and 12, Table 2).

Parents highlighted the importance of providing adequate preparatory information. They reported a need for detailed information regarding the management of their child’s condition (treatment, mechanisms of drug action and potential side effects) and the expected treatment outcomes. Furthermore, parents acknowledged a need for information regarding the psychological impact of admission (Quotes 13 and 14, Table 2).

### **Theme 2. The ward as a challenging environment**

As a consequence of the limited preparatory information, parents reported feeling ill-prepared for the changes in routine, the sense of isolation and the intensity of the ward setting. As previously noted, CF is a condition that requires a structured treatment regimen for effective disease management; parents therefore play a key role in maintaining adherence (Modi, Marciel, Slater, Drotar, & Quittner, 2008). Some parents reported difficulty adjusting to changes in routine, noting the “fluid” nature of the ward environment and associated lack of structure regarding medication and treatment delivery (Quotes 15 and 16, Table 2).



The privacy afforded by individual rooms was valued by some, as it allowed for an element of environmental control to be regained (Quote 17, Table 2). However, for others, this segregation evoked intense feelings of “isolation”, particularly for parents of younger children (Quote 18, Table 2). Although parents acknowledged the importance of segregation measures in reducing the chances of cross-infection, some perceived these measures as punitive. One parent, whose child was 20 months at the time of admission, compared the room to a “prison cell” in which she felt “trapped”.

The ward environment was described as “light” and “noisy”, with frequent disruptions taking place throughout the night. These environmental factors were associated with feelings of exhaustion (Quotes 19 and 20, Table 2).

Some parents spoke of the emotional impact of being on the ward and the difficulty in seeing sick and vulnerable children. One parent spoke of her distress in seeing an older child with CF, which aroused her own fears regarding the future (Quote 21, Table 2). These feelings were echoed by another parent who described the ward experience as a “reality check” raising awareness to the fact that her child had a serious chronic condition that could result in multiple hospital admissions.

A couple of parents recommended a pre-admission visit to the ward in order to build familiarity with the setting and therefore decrease anxiety (Quotes 22 and 23, Table 2).

### **Theme 3. Changes in the parent-professional relationship**

Admission to the ward brought with it not only a change in environment and routine but also a change in staff team. As with other aspects of the admission, parents reported feeling unprepared for this change (Quotes 24 and 25, Table 2). Parents reported a trusting and supportive relationship with their community CF team, having known them since their child’s diagnosis; one parent referred to them as “family” (Quote 26, Table 2).

This contrasted with the less individualised approach to care on the ward, with some parents feeling that senior professionals did not listen to them (Quote 27, Table 2), provide clear information regarding their child's treatment status (Quote 28, Table 2) or fully appreciate their anxieties regarding their child's admission (Quote 29, Table 2).

The need for more open and honest communication between senior physicians and parents in allaying anxiety and fostering trust was raised in several interviews. Also identified was the importance of informing parents of the changes in staff teams prior to admission (Quote 30, Table 2).

#### **Theme 4. The parental role in medical care**

All parents spoke of their need for involvement and participation in care. This theme describes the juxtaposition between two parental roles: active participant and passive observer. Lack of preparation and poor communication with senior ward staff left parents feeling disempowered and unsure of their role in care. For most parents, feeling in control was important; they perceived themselves as experts in their child's care and thus wanted to maintain a sense of "autonomy" (Quotes 31 and 32, Table 2).

For some parents, feeling as though they had to relinquish control to the medical team was perceived as frustrating (Quotes 33 and 34, Table 2). For others, a lack of clarity regarding their role on the ward led them to believe that their role was now redundant (Quotes 35 and 36, Table 2).

The ability to regain control came more easily to some than others. One parent found that communication and knowledge of the situation was fundamental in bringing her round to hospital life (Quote 37, Table 2). For another parent, learning to administer IV antibiotics and working closely with the staff team allowed her to take back some responsibility (Quote 38, Table 2). For one parent, however, taking "a step back for a little while" was seen as the appropriate response (Quote 39, Table 2).

Given their lack of preparation, most parents reported a desire for further information and knowledge. One parent spoke of her stress in not knowing (Quote 40, Table 2).

## **Discussion**

Hospital admission can be a daunting prospect for patients and their families (Litke, Pikulska, & Wegner, 2012). Current health policy promotes the need to inform parents of what to expect during their child's hospitalisation in order to allay fears and increase active participation in care (Department of Health, 2003). The findings of this research indicate that the majority of parents felt unprepared for their child's hospital admission; specifically, they reported a short time frame between being notified of admission and entering the ward. Furthermore, information was considered limited, addressing certain practical and medical aspects of admission, with minimal emphasis on the psychological and social implications.

Parents reported how inadequate preparation had an adverse impact on how they experienced their time on the ward. They reported feeling ill-prepared for the changes in the environment, routine, and staff team, resulting in anxiety, uncertainty and distress regarding their role in care. These findings support previous research that indicates hospital-related distress among parents of hospitalised children, especially during times of significant uncertainty (Kassam-Adams et al., 2009). Parental distress has been identified as a barrier to effective participation (Power & Franck, 2008) and has shown to impact negatively on the hospitalised child (Alisic et al., 2011; Dunn et al., 2012; Kassam-Adams et al., 2009; Nugent et al., 2007).

Evidence has shown that in such situations parents will often seek to reduce their anxieties by improving their knowledge of their child's treatment and negotiating new roles in care (Corlett & Twycross, 2006). For some parents in this study, forging new relationships with staff and actively seeking out opportunities to facilitate in care led to a positive hospital experience. For most, however, a lack of effective parent-professional communication and clearly articulated expectations from medical staff limited parents' capacity to participate actively in care. These findings

highlight some of the challenges associated with implementing a ‘family-centred care’ approach within routine clinical practice.

Consistent with previous research, parents reported that they would have appreciated timely, detailed and comprehensive information, addressing the full range of medical, practical and psychosocial implications of admission. In so doing, parents felt that they would be better equipped to cope with their child’s hospitalisation, adjusting their expectations accordingly and effectively preparing for admission (Chapados, Pineault, Tourigny, & Vandal, 2002; Conway et al., 2006; Franck & Spencer, 2005). Indeed, parental satisfaction with their child’s medical care has been found to be closely associated with their perception of adequacy of information provided (Magaret, Clark, Warden, Magnusson, & Hedges, 2002). Melnyk (1994) utilised a randomised controlled design to investigate the usefulness of pre-hospitalisation information in reducing parental anxiety and improving parental participation in care. Findings indicated that parents who received information about their child’s expected behaviour and their own optimal role in care (intervention group) were significantly less anxious during their child’s hospitalisation and were more supportive in care than parents who did not receive this information (control group).

### **Implications for clinical practice**

This study provides a valuable insight into parent’s experiences of their child’s initial hospital admission and has important implications for clinical practice. A key message arising from the interviews was the parents need to be perceived as joint advocates with clinicians for their child’s care, comfort and improved health. This fits with their perceived role as both ‘parent’ and ‘carer’ for their child, having developed expertise in the management of their child’s condition (Modi et al., 1998). Health care professionals have a role in assisting parents make informed decisions and to retain a sense of control over their child’s treatment. In order to facilitate this, there is a need for parents to have access to sufficient preparatory information prior to admission (e.g., in the form of a leaflet or DVD) and to have the freedom to openly discuss their concerns regarding their child’s healthcare during the hospital

stay (Appendices D reports specific recommendations for clinicians within the BRHC paediatric CF service).

## **Limitations**

This study has several limitations. A small sample size limits the generalisability of the themes and therefore service changes must be considered with some caution. Eleven of the twelve parents interviewed were White British; therefore issues relating to culture and ethnicity that may have affected parental experiences were not explored. A common critique of studies regarding parental experiences is the lack of fathers' views (Noyes, 1998). While the aim of the present study was to gain a general understanding of parents' concerns, no attempts were made to have an equal number of fathers and mothers. Two fathers were present during the interviews; however they contributed minimally to discussion, perhaps primarily because they reported having not stayed with their child during the hospitalisation. Conducting interviews with each parent separately may have helped overcome this issue.

While this study highlights parent perspectives of service delivery, the authors recognise that these can differ from clinician perspectives. For example, inadequate resources (e.g., low staff to patient ratio) can hinder clinicians' efforts in providing supportive services. Health care professionals could demonstrate an understanding of the plight of parents who may feel disempowered, ill-informed and strained by inadequate resources.

## **Conclusion**

The findings of this study indicate the importance of adequate preparatory information in reducing parental stress and influencing how future experiences are appraised and managed. Information must address all aspects of admission including the medical, practical *and* psychosocial implications. Effective parent-professional communication and opportunities to participate in care will improve parental satisfaction.

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**Main Research Project**

**Psychological Factors in Parkinson's Disease**

Vera Christina Fixter

Doctoral Programme in Clinical Psychology, Department of Psychology, University  
of Bath, Claverton Down, Bath, BA2 7AY, Tel: 01225 385506, Email:  
[vch23@bath.ac.uk](mailto:vch23@bath.ac.uk)

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Internal/Academic Supervisor:  
Professor Paul Salkovskis

External Supervisor:  
Dr Leon Dysch

**Proposed Journal:** Journal of Parkinson's Disease, a journal devoted to publishing original research in basic science, translational research and clinical medicine in Parkinson's Disease (see Appendix F for authors guidelines).

## Abstract

**Background:** Parkinson's Disease (PD) is neurodegenerative condition with an unpredictable prognosis. Although research indicates high levels of anxiety and depression among those with PD, few studies have focussed on more specific psychological factors such as anxiety focussed on health. **Objective:** The primary aim of this study was to evaluate the extent and impact of health anxiety on quality of life (QoL), psychological distress and perceived disability in patients with PD. **Method:** Fifty-five patients with PD completed questionnaires assessing health anxiety, mood, and QoL. Participants also completed tasks assessing cognitive and physical functioning and perceived performance. Participants with relatively high or relatively low health anxiety were compared with a non-PD community sample (N=32). **Results:** The high health anxiety PD group reported significantly lower QoL relative to both comparison groups independent of level of disability. They also reported elevated psychological distress (anxiety and depression). The PD groups were significantly impaired on both cognitive and physical endurance tasks relative to healthy controls, but only the high health anxious PD group *perceived* themselves as significantly impaired on the cognitive task. Neither PD group perceived their performance as impaired on the physical task. Health anxiety was found to be a better predictor of psychological distress relative to other contributory factors such as intolerance of uncertainty. **Conclusion:** Health anxiety may interact with the experience of PD in ways which impact on QoL, psychological distress and perceived disability. PD patients may also underestimate the impact of their illness on their physical impairment.

**Keywords:** Parkinson's disease; health anxiety; intolerance of uncertainty; psychological distress; quality of life.

## **Introduction**

Parkinson's Disease (PD) is a chronic neurodegenerative condition affecting approximately 127,000 people in the United Kingdom (Parkinson's UK, 2015). It is characterised by the profound and selective loss of dopaminergic neurons in the substantia nigra. As the disease progresses, increasing neuronal dysfunction affects the central, peripheral, and automatic nervous system resulting in more widespread impairment (Jellinger, 2012). Cardinal features of PD include resting tremor, slowness of movement, rigidity and postural instability (Jankovic, 2008). Non-motor symptoms are also present in those with PD, often predating the onset of motor symptoms and worsening with disease progression (Chaudhuri, Healy, & Schapira, 2006). These include psychological problems, cardiovascular and gastrointestinal difficulties, sleep disturbances and cognitive decline (Park & Stacy, 2009).

Although effective motor symptomatic control is possible with medical treatment in the early-to-mid stages, the majority of patients experience motor fluctuations (referred to as 'on-off' states) and increasing disability as the disease progresses, resulting in a gradual deterioration in health and cognitive status (Lang & Lees, 2002). A diagnosis of PD therefore represents the prospect of diminishing ability to perform basic daily activities, increased dependency and decreased predictability regarding one's symptoms and the future. Not surprisingly therefore, PD is a distressing and anxiety provoking condition for both patients and their carers (Peters, Fitzpatrick, Doll, Playford, & Jenkinson, 2011).

### **Parkinson's Disease and psychological symptoms**

Clinically, psychological difficulties are one of the most commonly reported non-motor symptoms of PD (Gallagher, Lees, & Schrag, 2010). Studies have indicated a higher prevalence of anxiety and depression in patients with PD compared to healthy age-matched controls (Chaudhuri et al., 2006) and individuals with other chronic conditions (Pincus & Tucker, 2003). It is estimated that depression affects 35% of all PD patients (Reijnders, Ehrt, Weber, Aarsland, & Leentjens, 2008) and up to 43% of patients suffer from a circumscribed anxiety disorder (Dissanayaka et al., 2010;

Leentjens et al., 2011; Menza, Robertson-Hoffman, & Bonapace, 1993; Pontone et al., 2009; Richard, 2005).

Psychological symptoms in PD have been found to have a negative effect on QoL (Carod-Artal, Vargas, & Martinez-Martin, 2007; Pachana et al., 2013; Schrag, 2006), cognitive functioning (Bogdanova & Cronin-Golomb, 2011; Norman, Tröster, Fields, & Brooks, 2014; Ryder et al., 2002), and existing motor symptoms (Chen & Marsh, 2013).

In general, it is argued that the increased prevalence of psychological symptoms in PD may be a consequence of interactions between (a) the neurodegeneration of neurochemical pathways involved in the regulation of mood and anxiety and (b) the psychological response to the physical symptoms and adverse effects of the disease (Dissanayaka et al., 2010). Given the distress associated with a diagnosis of PD and the unpredictability of disease outcome over time, researchers have argued that psychological factors may play a significant role in the emotional distress experienced by patients with PD (e.g., Burn et al., 2012; Quelhas & Costa, 2008). However, despite recent research focussing on the prevalence of anxiety and depression in PD (e.g., Pontone et al., 2009; Richard, 2005; Reijnders et al., 2008), few studies have focussed on the specific psychological factors and processes that may underpin emotional distress and psychological well-being in these patients (Dissanayaka, 2010).

### **Psychological mechanisms in Parkinson's Disease**

Given the unpredictable and degenerative nature of PD, it is likely that some patients will experience significant concerns about their health. Anxiety about health can be represented as a continuum, with minimal concern or absence of preoccupation with bodily symptoms at one end and extreme anxiety about one's health on the other (Warwick & Salkovskis, 1990). According to the cognitive behavioural model (Warwick & Salkovskis, 1990), health anxiety arises from a tendency to believe that perceived bodily variations are due to health problems which are more serious than is actually the case. This tendency is maintained by a series of processes

characterised by vicious circles which can include increased attention both to the body and medically relevant information and safety seeking behaviours such as excessive reassurance seeking. These can all reinforce the misinterpretation of perceived bodily variations, leading to further anxiety.

Although this model was developed for people without diagnosable disease but who do report health anxiety, there is some evidence that health anxiety is experienced by individuals with ongoing and unpredictable illness. Research has shown that individuals with heart disease, who had previously experienced heart attacks and scored highly on health anxiety measures, were more likely to think that common bodily sensations were due to their disease, compared to their counterparts without health anxiety (known as misattribution; Ratcliffe, MacLeod, & Sensky, 2006). Similarly, patients with upper respiratory tract infection and greater psychological distress paid closer attention to their bodily sensations (known as amplification; Barsky, Goodson, Lane, & Cleary, 1988).

Recent research has raised the possibility that similar mechanisms may occur among individuals with neurological conditions. Hayter, Salkovskis, Morris, and Silber (in press) investigated the prevalence of health anxiety among patients with relapsing-remitting multiple sclerosis (RRMS), a neurodegenerative disease with an unpredictable prognosis. The authors examined factors maintaining health anxiety in this population and the impact on self-reported QoL. Findings indicated that higher levels of health anxiety were associated with lower QoL scores and a tendency to attribute common bodily symptoms to disease factors. Further, when asked to complete a series of cognitive and physical endurance tasks, those with higher levels of health anxiety were more likely to perceive their performance negatively, attributing difficulty to their disease. These findings have been supported by a recent replication study (Carrigan, unpublished doctoral dissertation).

Similarly to patients with relapsing and remitting MS, patients with PD may experience their symptoms as unpredictable and threatening and therefore have an inclination to monitor their bodies and behaviour for possible signs of illness. This may lead to preoccupation and distress when such signs are detected. However, no

studies have investigated whether this understandable worry is severe enough to satisfy the criteria for health anxiety. If it is the case that patients with PD display high levels of health anxiety it would be interesting to investigate the impact on psychological well-being and QoL and explore potential maintenance factors.

The present study will also examine the relative contribution of health anxiety and intolerance of uncertainty (IoU; Dugas, Freeston, & Ladouceur, 1997) in predicting patient distress. IoU is a factor known to be associated with generalised anxiety and that might be relevant in predicting distress in patients with PD. IoU has shown to increase perceived stress and lead to poorer emotional wellbeing in cancer patients (Kurita, Garon, Stanton, & Meyerowitz, 2013; Taha, Matheson, & Anisman, 2012).

### **Study aims**

The aims of the present study are as follows: (i) to measure the extent of health anxiety in a sample of patients with early to mid-stage PD, (ii) to evaluate whether health anxiety adversely impacts QoL, even when controlling for level of disability, (iii) to evaluate whether health anxiety adversely impacts patient reported psychological distress (anxiety and depression), (iv) to evaluate the impact of health anxiety on perceived impairment of cognitive and physical performance and (v) to examine the relative contribution of psychological factors (health anxiety and IoU) in predicting psychological distress among patients with PD.

## **Method**

### **Design**

The main group comparison was between PD patients with relatively high or relatively low health anxiety. A healthy community sample (of similar age and gender) was recruited in order to benchmark the two group comparisons. Predictors of distress were evaluated in the PD groups only.

### **Power analysis**

Hayter et al. (in press) found a large effect size (1.1) in RRMS patients, utilising a total sample size of 42 (21 participants per group). Assuming similar but smaller effects in PD, the power analysis conducted using G\* Power indicated that with a large effect size (0.8) and an alpha level of 0.05, 52 PD patients (26 per group) would be needed to detect a significant result with an indicated power of 0.80.

### **Participants**

Forty-eight patients were recruited from Movement Disorder and Neurology out-patient clinics in the South West of England (Bath and Swindon) and a further ten patients were recruited through Parkinson's UK (registered charity). All patients were diagnosed with idiopathic PD by movement disorder specialists, according to the United Kingdom Brain Bank criteria. Participants were over the age of 18 years and had a mild to moderate level of disability as defined by a score of  $<2.5$  on the Hoehn and Yahr Scale (Hoehn & Yahr, 1967, as cited in Goetz et al., 2004). Patients were excluded from the study if they met any of the following criteria: (a) score of  $<22$  on the Montreal Cognitive Assessment (MoCA; Nasreddine, 2005) (indicating significant cognitive impairment) (b) history of secondary or atypical Parkinsonism, (c) presence of a complex/severe mental health problem or (d) evidence of co-morbid acquired brain injury. Three patients were excluded on the basis of exclusion criteria (a), leaving a total sample of 55 participants. Thirty-two healthy control participants were recruited into the study using a research advertisement distributed within community settings (e.g., local social clubs). Written informed consent was gained from all participants at the time of recruitment.



## Measures

### *Disability and disease severity*

*Movement Disorder Society Unified Parkinson's disease Rating Scale Part II* (MDS-UPDRS; Goetz et al., 2007). The MDS-UPDRS is a patient rated measure of PD motor symptoms. Higher scores indicate greater disability. The MDS-UPDRS has good psychometric properties (Goetz et al., 2008).

*Hoehn and Yahr Scale* (HY; Hoehn & Yahr, 1967, as cited in Goetz et al., 2004). The HY is a standard clinical index of PD motor stage. It globally indexes signs and symptoms of functional impairment, including postural instability, rigidity, tremor, and bradykinesia. The HY has demonstrated moderate to significant levels of inter-rater reliability (Geminiani et al., 1991; Ginanneschi et al., 1991).

### *Mood*

*Hospital Anxiety and Depression Scale* (HADS; Zigmond & Snaith, 1983). The HADS is a 14-item self-report measure of anxiety and depression. Subscale scores can be computed for depression and anxiety, scores of 8-10 indicate 'possible' depression or anxiety, and >11 a 'definite' problem. The HADS has been validated for use in PD (Mondolo et al., 2006; Rodriguez-Blazquez, Frades-Payo, Forjaz, de Pedro-Cuesta, & Martinez-Martin, 2009).

### *Health anxiety*

*Short Health Anxiety Inventory* (SHAI; Salkovskis et al., 2002). The SHAI is a 14-item measure of health-related anxiety. Participants choose one of four statements for each item which relates best to their health related thoughts and behaviours. A cut-off score of 18 or greater indicates clinical levels of health anxiety (Seivewright et al., 2004), a score of 15 suggests symptoms of health anxiety. The SHAI has good reliability and validity (Salkovskis, Rimes, Warwick, & Clark, 2002). The SHAI was modified for PD with the author's permission. This involved adding "other than

PD,” to items 5, 9, 11, and 12 so that participants’ responses were not limited by already having a serious health condition (e.g., “as a rule, I am not afraid that I have a serious illness [other than PD]”).

#### *Intolerance of uncertainty*

*Intolerance of Uncertainty Scale Short Form* (IUS-12; Carleton, Norton, & Asmundson, 2007). The IUS-12 is a 12-item measure. Items are scored on a 5 point Likert scale ranging from 1 (not at all characteristic of me) to 5 (entirely characteristic of me), higher scores reflect higher levels of IoU. The IUS-12 has shown to have excellent internal consistency and convergent validity with the original version (Carleton, Norton, & Asmundson, 2007).

#### *Quality of life*

*Ferrans and Powers Quality of Life Index* (QLI; Ferrans & Powers, 1992). The QLI is a 37-item self-report measure that assesses an individual’s satisfaction with various domains of life, taking into account their relative importance to the respondent. Items are rated on a 6 point Likert scale (1 = very dissatisfied to 6= very satisfied), scores range from 0-30. Higher scores reflect higher levels of QoL. The QLI has been used in studies of various physical health conditions, and possesses good internal consistency and concurrent validity (Ferrans & Powers, 1985).

#### *Cognition functioning*

Executive function deficits are observed in PD patients even relatively early on in the disease process (Emre, 2003).The Brixton Spatial Anticipation Test (BSAT; Burgess & Shallice, 1997) was used as a measure of executive functioning. This task is designed to measure rule attainment, flexibility of thinking and appropriate switching of behaviour. The BSAT is a valid and reliable measure which is widely used in the general and PD population to indicate difficulty with planning and following rules.

### *Physical Functioning*

A hand grip dynamometer was used to measure hand strength and endurance. The protocol for using the hand grip dynamometer followed that used by Hayter et al. (in press) and is based on that used in a study investigating people with chronic pain (Rode, Salkovskis, & Jack, 2001). The hand grip task has been used in the literature to measure hand strength in patients with PD (e.g., Roberts, Syddall, Butchart, Stack, Cooper, & Sayer, 2015).

### *Misperception and Misattribution of task performance*

Misperception of performance on the cognitive and physical tasks was assessed using a similar measure to the one developed in the Hayter et al. study (in press). Following the physical and cognitive tasks, participants were asked to evaluate how well they felt they had performed compared to individuals in the general population on a scale from -50 (“extremely badly in comparison to others”) to +50 (“extremely well in comparison to others”). They then completed a measure of how worried they were about their performance 0 (“not worried at all”) to 100 (“extremely worried”) and how much better they felt their performance on the tasks would have been if they did not have PD, from 0 (“no better”) to 100 (“very much better”).

### **Procedure**

Clinicians identified eligible participants from their caseload. Within routine clinic appointments or during home visits, eligible participants were invited to take part in the research. It was made clear that individuals were under no obligation to participate and that they could withdraw at any time.

Once written informed consent was obtained, participants were contacted by telephone by the lead researcher to arrange a formal research session. Participants were free to choose whether this session took place within their own home or at one of the allocated outpatient clinics. Prior to the formal research session, participants

were sent a questionnaire pack to complete. During the research session, participants completed the assessment of physical and cognitive functioning before completing subjective ratings of their performance. The session took approximately 1 hour. The same procedure took place using healthy controls.

## **Ethics**

Ethical approval for the study was obtained from the Wales NHS Research Ethics Committee (ref: 14/WA/0193) and the University of Bath's Department of Psychology Ethics Committee.

## **Statistical analysis**

Statistical analysis was performed using SPSS for Windows 21. High health anxious (HiHA), low health anxious (LowHA) and healthy control (HC) groups were compared using ANOVAs (with ANCOVAs where appropriate) for three group analyses. Where within subjects elements were included in analyses, mixed model ANOVAs were used, with simple main effects analyses used to interpret interactions when present. The alpha level was set at .05 for statistical significance for all tests. Multiple comparisons used Least Significant-Difference (LSD), except when Levene's test for homogeneity of variance was significant, in which case Dunnett's T3 test was used. For categorical variables, chi-squared analyses were used to determine whether there were statistically significant differences between groups ( $\alpha = .05$ ).

Linear step-wise regression analysis was carried out to examine predictors of patient psychological distress (anxiety and depression) for the entire PD sample. IoU, SHAI, and UPDRS Part II total scores, age, MoCA and Hoehn and Yahr scores were used as predictor variables and the HADS total as the dependant variable.

## Results

### Sample characteristics

The PD sample consisted of 27 males (49%) and 28 females (51%) with a mean age of 66.6 years (range = 38-86, SD=8.45). All participants identified themselves as White British. Patients had a median Hoehn & Yahr score of 1.5 (range = 1.0-2.5). The average duration of PD was 3.45 years (range = 0.5-18 years, SD=3.61) (see Table 1). Eighty percent of the sample was using Levodopa, and 55% were also receiving adjunctive anti-Parkinsonian medications, including dopamine receptor agonists, MAO-B inhibitors and COMT inhibitors. Nine percent of patients were on no anti-parkinsonian medication.

The total PD sample had a mean score of 11.82 (SD = 5.74) on the Short-Health Anxiety Inventory (SHAI). For the main analysis, high health anxiety (HiHA) was defined as a score of 14 or greater; low health anxiety (LowHA) was defined as a score of 12 or less. These cut-off values were based on a median split of the data with the middle two values removed. This allowed for reasonable confidence in the group separation (SE = 0.55). This method was used in place of using clinical cut-off values for the SHAI as too few participants fell in the high health anxiety range.

This meant that for group comparisons, the HiHA group comprised of 21 PD patients, and the LowHA group comprised of 32 PD patients. For other analyses, the two participants that fell between these two zones were included. Thirty-two healthy controls had a mean score of 9.41 (SD = 4.46) on the SHAI.

As can be seen in Table 1, the HiHA, LowHA, HC groups showed no statistically significant differences in age ( $F_{(2, 84)} = 1.71, p, p>.05$ ), gender ( $\chi^2_{(2)} = .573, p>.05$ ), or scores on the cognitive screen (MoCA) ( $F_{(2, 84)} = 1.27, p>.05$ ). Groups did differ significantly in terms of the number of years spent in formal education ( $F_{(2, 84)} = 7.22, p, p<.05$ ). Multiple comparisons indicate that both PD groups spent less years in formal education compared to the HC group ( $p<.01$ ). HiHA and LowHA did not differ significantly from one another ( $p>.05$ ). The samples were comparable in terms of demographics, with the exception of the control group who spent more years in formal education.

Table 1. Means (SDs) of sample characteristics, PD-related variables and scores on questionnaire measures

	PD (LowHA) (N=32)	PD (HiHA) (N=21)	HC (N=32)
Sample characteristics	Mean (SD)	Mean (SD)	Mean (SD)
Age	67.34 (9.92)	65.90 (6.05)	63.78 (6.07)
Gender	53.1% male, 46.9% female	42.9% male, 57.1% female	46.9% male, 53.1% female
Years in Education (since the age of 12)	7.09 <sup>a</sup> (3.71)	6.76 <sup>a</sup> (3.11)	9.69 <sup>b</sup> (2.72)
MoCA score	27.06 (2.18)	26.71 (1.85)	27.56 (1.76)
PD-related variables			
Hoehn & Yahr Scale Score	1.66 (0.48)	1.86 (0.50)	
UPDRS Part II	9.66 (7.48)	11.71 (6.38)	
Years since diagnosis	2.96 (2.79)	3.52 (3.48)	
Years since symptom onset	3.93 <sup>a</sup> (2.92)	6.45 <sup>b</sup> (4.38)	
Questionnaire measures			
HAI	7.81 <sup>a</sup> (2.90)	17.81 <sup>b</sup> (3.54)	9.41 <sup>a</sup> (4.46)
QLI	22.11 <sup>a</sup> (4.45)	17.32 <sup>b</sup> (3.77)	23.45 <sup>a</sup> (3.80)
HADS Total	8.78 <sup>a</sup> (5.71)	15.05 <sup>b</sup> (5.47)	6.81 <sup>a</sup> (4.70)
HADS A	5.38 <sup>a</sup> (3.89)	8.67 <sup>b</sup> (3.35)	4.94 <sup>a</sup> (3.34)
HADS D	3.41 <sup>a</sup> (2.66)	6.38 <sup>b</sup> (2.91)	1.88 <sup>a</sup> (2.08)
IUS	22.59 <sup>a</sup> (6.81)	29.52 <sup>b</sup> (10.20)	21.94 <sup>a</sup> (5.62)

*Note:* Means sharing a subscript are not significantly different from each other ( $p > .05$ ). Means sharing dissimilar subscripts differ significantly ( $ps < .05$ ).

## **PD-related variables**

As can be seen in Table 1, the two PD groups (HiHA and LowHA) showed no statistically significant differences in time since diagnosis ( $F_{(1, 52)} = .42, p > .05$ ), disability status ( $F_{(1, 52)} = 1.08, p > .05$ ; measured on UPDRS Part II) or disease stage ( $F_{(1, 52)} = 2.12, p > .05$ ; measured using the Hoehn and Yahr Scale). There were significant differences in reported years since symptom onset ( $F_{(1, 52)} = 6.37, p < .05$ ). The two groups were comparable, with the exception that the HiHA group reported a longer duration of PD symptoms.

## **Questionnaire measures**

### *Quality of life*

In the first analysis, PD participants were compared with healthy controls on QoL, as measured by the QLI. In a one-way ANOVA there was a significant main effect of group on QLI scores,  $F_{(1, 86)} = 11.70, p < .001$ , with PD participants having lower scores overall. The three group comparison (HiHA, LowHA and HC) also showed a significant main effect of group,  $F_{(2, 84)} = 15.24, p < .0001$ . Multiple comparisons indicate that impaired QoL was confined to the HiHA group, who reported significantly lower QoL than the LowHA group ( $p < .0001$ ) and the HC ( $p < .0001$ ), who did not significantly differ ( $p > .05$ ) (see Table 1).

An ANCOVA was carried out comparing the HiHA and LowHA PD groups, covarying for level of disability (as measured by Part II of UPDRS). This showed a main effect of group;  $F_{(1, 50)} = 17.41, p < 0.001$ . Adjusted QoL means for high and low health anxiety groups were 17.75 and 21.83 respectively. As the UPDRS Part II is a self-report measure a further covariance analysis was conducted, this time using the Hoehn and Yahr score, a clinician rated measure of disability. This analysis showed a main effect of group;  $F_{(1, 50)} = 14.20, p < .0001$ . Adjusted QoL means for high and low health anxiety were 17.49 and 22.01 respectively.

### *Psychological distress*

In the second main analysis, the three groups (HiHA, LowHA and HC) were compared on levels of psychological distress, as measured by the HADSA and HADSD. This analysis utilised a 2 (HADSA, HADSD) by 3 (HiHA, LowHA, HC) mixed model ANOVA revealing a significant effect of subscale  $F_{(1, 82)} = 47.97$ ,  $p < .0001$  and of group  $F_{(2, 82)} = 15.97$ ,  $p < .0001$ , with the group by subscale interaction not significant ( $F < 1$ ). Regardless of group, HADSA was significantly higher than HADSD. In order to evaluate the group effect, a further one-way ANOVA was carried out on HADS total;  $F_{(2, 84)} = 15.97$ ,  $p < .0001$ . Multiple comparisons indicate that the HiHA reported significantly higher HADS total scores compared to the LowHA group ( $p < .0001$ ) and the HC group ( $p < .0001$ ); who did not significantly differ ( $p > .05$ ) (see Table 1).

### **Cognitive and physical tasks**

#### *Objective performance on cognitive and physical tasks*

Actual performance on the cognitive and physical tasks were first analysed in order to determine degree of impairment. A one-way ANOVA comparing all three groups on the Brixton showed a significant main effect of group,  $F_{(2, 84)} = 10.78$ ,  $p < .0001$ . Multiple comparisons indicated that both LowHA and HiHA groups were impaired compared to HC ( $p < .05$ ) and did not differ from each other ( $p > .05$ ).

A one-way ANOVA comparing all three groups on the Hand Grip Endurance Task showed a significant main effect of group,  $F_{(2, 84)} = 7.16$ ,  $p < .001$ . Multiple comparisons indicated that both LowHA and HiHA groups were impaired compared to HC ( $p < .05$ ). The HiHA and LowHA groups were not significantly different to each other ( $p > .05$ ). These results indicate similar levels of impairment in both PD groups relative to controls on both tasks (see Table 2).



Table 2. Mean (SD) scores for the cognitive and physical tasks across groups

	PD (LowHA) (N=32)	PD (HiHA) (N=21)	HC (N=32)
Cognitive task: Brixton (scaled score)	4.22 <sup>a</sup> (2.14)	3.95 <sup>a</sup> (2.42)	6.09 <sup>b</sup> (1.17)
Physical task: Hand Grip Endurance (seconds)	86.64 <sup>a</sup> (44.40)	81.03 <sup>a</sup> (36.89)	116.43 <sup>b</sup> (31.59)

*Note:* Means sharing a subscript are not significantly different from each other ( $p > .05$ ). Means sharing dissimilar subscripts differ significantly ( $ps < .05$ )

#### *Perceived performance on cognitive and physical tasks*

Having established comparability on actual task performance, perceived performance was then analysed. A 3 (HiHA, LowHA, HC) by 2 (performance ratings on Brixton, Hand Grip Endurance Tasks) mixed model ANOVA revealed that there was a significant main effect of group on perceived task performance;  $F_{(2, 82)} = 3.22$ ,  $p < .05$ . There was also a significant main effect of task type on perceived task performance;  $F_{(1, 82)} = 6.94$ ,  $p = .01$ . The interaction between group and task type was not significant;  $F_{(2, 82)} = 1.74$ ,  $p = .18$ . Multiple comparisons across performance ratings (Brixton and Hand Grip Endurance Task) revealed a significant difference between the HiHA PD group and HC ( $p < .05$ ), with no other multiple comparisons being significant.

A supplementary simple main effects analysis indicated a significant main effect of group on perceived task performance on the Brixton,  $F_{(2, 84)} = 3.50$ ,  $p < .05$ ; multiple comparisons indicated that the HiHA group reporting poorer performance relative to the HC group ( $p < .05$ ) but not the LowHA group, which also did not differ from the HC ( $p > .05$ ) (see Table 3). By contrast, a one-way ANOVA failed to reveal a significant main effect of group on perceived task performance on the Hand Grip Endurance Task,  $F_{(2, 84)} = .99$ ,  $p > .05$ .

A 3 (HiHA, LowHA, HC) by 2 (worry over performance ratings on Brixton, Hand Grip Endurance Tasks) mixed model ANOVA revealed that there was a significant

main effect of group on perceived worry regarding task performance;  $F_{(2, 82)} = 6.75$ ,  $p < .05$ . There was also a significant main effect of task type on perceived worry over task performance;  $F_{(1, 82)} = 47.82$ ,  $p < .0001$ . The interaction between group and task type was not significant;  $F_{(2, 82)} = .92$ ,  $p > .05$ . Multiple comparisons across performance ratings (Brixton and Hand Grip Endurance Task) revealed a significant difference between the HiHA PD group and HC, ( $p < .001$ ), and between the low HA PD group and HC ( $p < .05$ ). There was no difference between HiHA and LowHA groups. Further, an independent groups t-test revealed no significant difference between the two PD groups on how much better they thought they would have performed on the Brixton had they not had PD ( $t_{(51)} = -1.27$ ,  $p > .05$ , two-tailed; Table 3).

Table 3. Participants' subjective ratings (Mean and SD) of their performance on the cognitive and physical tasks

	PD (LowHA) (N=32)	PD (HiHA) (N=21)	HC (N=32)
Cognitive task			
Perceived performance (-50 to +50)	-4.06 <sup>a, b</sup> (22.41)	-8.57 <sup>a</sup> (24.55)	5.63 <sup>b</sup> (14.13)
Worry about performance (0 to 100)	34.38 <sup>a, b</sup> (30.26)	44.76 <sup>a</sup> (26.20)	20.94 <sup>b</sup> (26.07)
Performance improvement if no PD (0 to 100)	29.38 (30.15)	39.52 (25.39)	NA
Physical task			
Perceived performance (-50 to +50)	8.75 (17.55)	1.90 (18.06)	6.25 (16.61)
Worry about performance (0 to 100)	13.13 (18.22)	19.52 (20.37)	5.63 (12.68)
Performance on improvement if no PD (0 to 100)	30.31 (27.88)	45.71 (31.71)	NA

*Note:* Means sharing a subscript are not significantly different from each other ( $p > .05$ ). Means sharing dissimilar subscripts differ significantly ( $ps < .05$ )

### Stepwise regression analyses allowing all predictors to compete for variance

In order to evaluate the relative contribution of psychological factors (health anxiety and IoU) and other variables of interest in predicting psychological distress across the entire PD group, a stepwise linear regression analysis was used. Collinearity statistics and diagnostics were conducted. None of these analyses suggested that multicollinearity was a cause for concern. IoU, SHAI and UPDRS Part II total scores, age, MoCA and Hoehn and Yahr scores were used as predictor variables and the HADS total score was used as the dependant variable. The first variable to enter was HAI total, accounting for 43% of the variance in scores on the HADS (adjusted  $R^2 = 0.43$ ,  $\beta = 0.66$ ,  $P = < 0.001$ ). The second variable entered was the UPDRS Part II total (adjusted  $R^2 = .57$ ,  $\beta = .40$ ,  $P = < 0.001$ ). The  $R^2$  change attributable to the UPDRS was .15. The third and final variable entered was IoU total (adjusted  $R^2 = .61$ ,  $\beta = .24$ ,  $p=.02$ ). The  $R^2$  change attributable to the IoU was .04. The three variables together had an adjusted  $R^2$  of .61 (see Table 4).

Table 4. Stepwise regression results for variables predicting psychological distress

	<b>B</b>	<b>SE B</b>	<b><math>\beta</math></b>
Step 1			
Constant	2.84	1.50	
SHAI Total	0.73	0.11	.66***
Step 2			
Constant	0.58	1.40	
SHAI Total	0.62	0.10	.56***
UPDRS Part II Total	0.34	0.08	.40***
Step 3			
Constant	-2.18	1.75	
SHAI Total	0.51	0.11	.46***
UPDRS Part II Total	0.30	0.08	.36***
IoU Total	0.17	0.07	.24*

Note:  $R^2 = .43$  for Step 1( $p<.0001$ );  $\Delta R^2 = .15$  for Step 2( $p<.0001$ );  $\Delta R^2 = .04$  for Step 3 ( $p<.05$ ) \*  $p<.05$ , \*\* $p<.01$ , \*\*\* $p<.0001$

## Discussion

This study evaluated the extent of health anxiety in a sample of patients with PD and examined the impact of health anxiety on QoL, psychological distress and perceived task performance.

Results indicated that overall, patients with PD experienced significantly greater levels of health anxiety than healthy controls. When the high and low health anxiety groups were compared, there were no differences in level of patient or clinician rated disability. However, the high health anxiety group reported lower QoL and greater psychological distress. The low and high health anxiety PD groups were similarly and substantially impaired on both cognitive and physical endurance tasks relative to healthy controls. Patients with PD and higher levels of health anxiety reported poorer perceived performance on the cognitive task and greater worry about their performance relative to healthy controls, although they did not differ significantly from low health anxious PD patients. Interestingly, despite their actual impairment, neither PD group perceived their performance on the physical task as impaired. When psychological factors (health anxiety and IoU) were entered into a stepwise regression analyses along with other potential predictors, health anxiety proved to be the most significant predictor of psychological distress.

Given that many patients with PD eventually experience significant disability, their psychological distress and lower QoL is understandable. However, the extent of these problems was found to be related to health anxiety more than actual impairment. Similarly, previous studies involving PD patients have found general anxiety and depression to be significant predictors of QoL rather than cognitive status or motor stage (Hanna & Cronin-Golomb, 2012; Carod-Artal, Ziolkowski, Mourao, Mesquita, & Martinez-martin, 2008; Quelhas & Costa, 2008). The results of the present study are consistent with the primary findings of Hayter et al. (in press) and Carrigan (unpublished doctoral dissertation) who found that among a group of patients with relapsing remitting MS, higher levels of health anxiety were associated with significant reductions in QoL and psychological wellbeing, and that this effect was evident when disability status was controlled.

In the present study, patients with high health anxiety correctly perceived their performance on the cognitive task as impaired relative to healthy controls, but in contrast to the findings of Hayter et al. (in press) both PD groups actually underestimated impairment on the physical task to similar levels.

Consistent with the view that patients underestimated performance on the physical task, there is evidence to suggest that dopaminergic treatment may have an impact on subjective perceptions of motor function. Amanzio et al. (2010) explored the effects of dopaminergic medication on awareness of motor dysfunction in a sample of PD patients experiencing motor fluctuations. These authors found that patients showed reduced awareness of evident movement disorder (dykinesias) in the 'on' state (state of optimal drug efficacy), as demonstrated by a discrepancy between patient and professional ratings of symptom severity. Conversely, patients displayed preserved awareness of evident movement disorder (hypokinesias) and associated psychological distress, in the 'off' state (state of decreased drug efficacy). The authors hypothesised that dopaminergic treatment may have a detrimental influence on the function of the orbitofrontal and cingulate frontal-subcortical loops; whose projections appear to be critical in the awareness phenomenon (Leritz et al., 2004; Seltzer et al., 2001). Eighty percent of patients recruited into the present study were taking Levodopa. Further, patients were tested when on medication to ensure their optimal motor state and to minimise motor demands. It is possible therefore, that medication may have had an effect on perceived performance.

Further, the sample comprised of patients with early to mid-stage disease: the mean duration of symptoms was approximately three years. Effective symptomatic control of motor and non-motor symptoms during the early stages of the disease is possible with dopaminergic medication (Lang & Lees, 2002). It is possible that, in the absence of objective feedback on performance and with patients perceiving symptoms as relatively well controlled under medication, they overestimated their performance on the physical task.

## **Limitations**

While the number of participants recruited into the study matched that indicated in the initial power calculation, the sample size was still relatively small. The study focussed on a specific subgroup of patients with PD (those with early-to mid-stage disease). As a result, caution is needed when generalising these findings to the PD population more broadly. A further issue was how participants were allocated to groups. The total PD group was divided into those with SHAI scores of 14 or greater or 12 or less. In the study by Hayter et al. (in press), patient groups were divided into those meeting criteria for hypochondriasis (scoring >18) and those without evidence of health anxiety (scoring <10), hence there was a larger difference between the two groups. It is possible that other significant differences between the two PD groups may have been found had the disparity in health anxiety scores been greater. However, note that the standard error of the HAI in the PD groups was 0.55, allowing reasonable confidence in the group separation.

## **Future research**

Although this research indicates that health anxiety has an adverse impact on QoL among patients with PD, this study does not provide an indication as to the specific mechanisms involved in this relationship. It would be useful for future studies to explore the cognitive (e.g., attentional biases) and behavioural (e.g., safety seeking behaviours) mechanisms through which health anxiety impacts on QoL in these patients (see Warwick & Salkovskis, 2002).

The study included self-report measures. Given potential discrepancies between objective and perceived performance among PD patients, future studies may wish to utilise alternative collection approaches, such as multiple informant measures and more comprehensive clinician rated measures of disability (e.g., UPDRS Part III). Further, future studies may wish to explore alternative measures of performance, potentially utilising functional every-day tasks to ensure ecological validity.

Individuals in the high health anxiety group retrospectively reported having experienced PD symptoms for a longer duration of time. Given this information was self-reported it is not possible to determine whether this was indeed the case or

whether health anxiety and associated cognitive processes (e.g., attentional biases) may have influenced participants' perceptions. A prospective investigation may help elucidate this point further.

Finally, given the potential influence of dopaminergic treatment on perceived performance, future studies may wish to assess patients both on and off medication. This could be achieved by assessing patients prior to their first daily dose of Levodopa. It may also be interesting to incorporate measures of movement disorder awareness (see paper by Amanzio et al., 2010).

### **Clinical Implications**

The findings of this study indicate that health anxiety may be a significant issue among patients with PD. Given the adverse impact of health anxiety on QoL and psychological distress, as well as the concomitant cost of health anxiety to health services (Tyrer et al., 2011), clinicians would benefit from routinely screening patients for health anxiety.

The findings suggest the potential benefit of cognitive-behavioural approaches for treating health anxiety (CBT-HA) in those with PD. Research indicates the effectiveness of CBT-HA in general and there is accumulating evidence that it can be applied to physical health settings (Salkovskis & Warwick, 2001; Tyrer et al., 2011). Given the presence of cognitive impairment in this group, adaptations to the standard CBT-HA protocol may be required. There is evidence to suggest the benefit of tailored cognitive-behavioural interventions for the treatment of anxiety and depression in patients with PD (e.g., Armento et al., 2012; Dobkin, Allen, & Menza, 2007; Dobkin et al., 2011; Veazey, Cook, Stanley, Lai, & Kunik, 2009). The effectiveness of such interventions could be assessed in the first instance, using a consecutive single case series A–B design. A similar approach has been taken in the area of relapsing remitting MS (e.g., Carrigan, unpublished doctoral dissertation).

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## **Executive Summary**

### **Background**

Parkinson's Disease (PD) is neurodegenerative condition with an unpredictable prognosis, impacting on all areas of life. Although research indicates high levels of anxiety and depression among those with PD; few studies have focussed on more specific psychological factors such as anxiety focussed on health. The primary aim of this study was to evaluate the extent and impact of health anxiety on quality of life (QoL), psychological distress and perceived disability in patients with PD.

### **Method**

Fifty-five patients with PD took part in the study. Participants were asked to complete questionnaire measures assessing health anxiety, mood, and QoL. Participants were also asked to complete two tasks assessing cognitive and physical functioning with measures taken of actual and perceived performance. Participants with relatively high or relatively low health anxiety were identified for purpose of analysis. A community sample of similar age and gender (N=32), not suffering from PD, were recruited in order to allow comparisons to be made between patients with PD and healthy controls.

### **Results**

The high health anxiety PD group reported significantly lower QoL relative to both comparison groups, independent of level of disability. They also reported elevated psychological distress (anxiety and depression). The PD groups were significantly impaired on both cognitive and physical endurance tasks relative to healthy controls, but only the high health anxious PD group perceived themselves as significantly impaired on the cognitive task. Interestingly, neither PD group perceived their performance as impaired on the physical task. Health anxiety was found to be a better predictor of psychological distress relative to other contributory factors such as one's ability to tolerate uncertain events or level of disability.

## **Implications for research**

- Although this study indicates that health anxiety has an adverse impact on QoL among patients with PD, it does not provide an indication as to the specific mechanisms involved in this relationship. Future studies would benefit from exploring the cognitive and behavioural mechanisms through which health anxiety impacts on QoL in patients with PD.
- Given the potential discrepancies between objective and perceived performance among patients with PD, future studies may wish to utilise alternative collection approaches, such as multiple informant measures and more comprehensive clinician rated measures of disability.
- Future studies may wish to explore alternative measures of performance, potentially utilising functional every-day tasks to ensure ecological validity.

## **Clinical Implications**

- Given the adverse impact of health anxiety on QoL and psychological distress, as well as the concomitant cost of health anxiety to health services, clinicians would benefit from routinely screening for health anxiety in PD.
- The findings suggest the potential benefit of cognitive-behavioural approaches for treating health anxiety (CBT-HA) in those with PD.
- Given the presence of cognitive impairment in this group, adaptations to the standard CBT-HA protocol may be required. There is evidence to suggest the benefit of tailored cognitive-behavioural interventions for the treatment of anxiety and depression in patients with PD.



## **Connecting Narrative**

Prior to training I worked primarily within the areas of adult neuropsychology and clinical health psychology. I have maintained my interest in these areas throughout my training and this is reflected in my choice of research projects. My main research project focusses on the area of Parkinson's disease, whilst my literature review and service improvement project focus on the clinical health areas of chronic fatigue syndrome and cystic fibrosis.

### **The Research Process**

#### *Critical Review of the Literature*

My critical literature review focussed on the relationship between perfectionism and chronic fatigue syndrome (CFS). Prior to training I worked as an Assistant Psychologist within a Chronic Pain and Fatigue Management Service for one and a half years. During my time there, I frequently co-facilitated groups in which I would introduce the cognitive behavioural model of CFS (Surawy et al., 1995) and discuss the role of personality factors (particularly unhealthy perfectionism and achievement striving) as predisposing and maintaining factors of the condition. I was intrigued to notice that in some cases clients really responded to this explanation, noting that they harboured high-self standards that may have exacerbated their symptoms, whereas others did not relate to this at all. Further, within the service where I worked no specific cognitive behavioural strategies for modifying unhelpful perfectionistic beliefs were offered. I felt that the generation of a critical review document that synthesised research on this topic would be helpful for clinicians and researchers alike in deciding whether perfectionism was an important personality factor to target for intervention.

Conducting the narrative review allowed me to appreciate the limited body of research currently focussed on the role of perfectionism in CFS, particularly studies using prospective or experimentally-based designs. This was indeed surprising given the heavy reliance on perfectionism as a suggested predisposing and maintaining factor in both the cognitive behavioural and psychodynamic models of CFS. I felt this review was therefore helpful in determining where the current research literature

is with regard to the role of perfectionism in CFS and in highlighting potential avenues for future research.

The literature review was one of the most challenging pieces of coursework I have completed so far. It required time to fully immerse myself in the research literature in order to critically evaluate the papers and reflect on the evidence base. Further, I was aware of the importance of ensuring that the method and acquisition of papers was conducted in a systematic fashion with clearly defined inclusion and exclusion criteria to help guide my search. I had helpful meetings with my course supervisor, Dr James Gregory and received invaluable expert input from Dr Kate Rimes, who has a special interest in perfectionism and CFS.

#### *Service Improvement Project*

During the first year of training, the course held a research fair. The purpose of this was to enable trainees to meet with local clinicians to discuss potential research projects. I was keen to meet with clinicians who shared my interest in clinical health and neuropsychology. Unfortunately, the research fair fell on a day when a regional clinical health network meeting was also taking place; as such it was not possible to meet with local clinicians directly.

Instead, we were provided with the contact details of all clinicians who had registered an interest in conducting research. I proceeded to contact all those whose interests were in line with my own, with a view to finding a service that would be open to service improvement. Dr Samantha Phillips, from the Cystic Fibrosis Service at the Bristol Children's Hospital, had supervised a trainee clinical psychologist in the previous cohort and wished to continue service improvement within her department. We met on several occasions to discuss potential research ideas. One of these was to follow-up on the work of the previous trainee, looking at improving transition arrangements from paediatric to adult services. However, when this idea was taken to the multi-disciplinary team (MDT) meeting it was felt that there were other areas that could benefit from renewed input. On reflection, earlier consultation with the MDT would have been helpful. This would have ensured that a team

consensus was reached at an earlier stage, improving the overall efficiency of the project.

I facilitated a team discussion in which we brainstormed potential ideas: At the end of the meeting all members agreed that a service improvement project focussing on the pre-hospitalisation information needs of parents of children with Cystic Fibrosis, would be a useful and interesting project. The team explained that at the time, parents were being directed to online materials which offered generic practical advice but did not address their psychological and social needs. Given the stress associated with child hospitalisation it was agreed provision of adequate resources was highly important.

Together with the team it was agreed that the project would focus on exploring the experiences of parents whose children had recently been admitted for their first course of intravenous antibiotics. This was seen as an important admission experience as it was usually the first time the child had been admitted to hospital since infancy. It was likely that this experience would raise many fears and anxieties, drawing greater attention to the fact that the child had a serious chronic condition for which future hospital admissions could be necessary.

My supervisor and I agreed that a qualitative design would be best suited to yield rich data and capture the reality of the parents' experiences. Time was spent with Dr Phillips and the team devising stem questions that would form the topic guide for the semi-structured interview. I found this a really useful experience; the teams' expertise yielded clear questions designed to explore parents' feelings regarding existing materials and areas for service improvement. This process also allowed all members of the MDT to contribute to the research. Unfortunately, service users were not consulted during the development of the research.

Recruitment into the study was relatively straightforward. Ethical approval was sought from both the University of Bath and the participating NHS Trust. I was fortunate in that the team had strong relationships with its paediatric clients and their families and as such we were able to recruit a good number of parents into the project successfully.

Conducting the semi-structured interviews required skill in ensuring that I maintained an objective stance and did not influence the participants' responses. I tried to be mindful of the distinction between 'researcher' and 'therapist' roles throughout the interview process. On reflection, more supervision or specific teaching on how to conduct semi-structured interviews might have been helpful.

I found analysing the data and developing themes the most challenging aspect of the project, yet also a highly useful experience and greatly appreciated input from my supervisors regarding this.

Following completion of the project, I was able to return to the service and feedback my findings; this was a very rewarding experience. The results of the project highlighted a number of useful recommendations for the service, which the team were very happy to action.

Prior to training, I had only completed one qualitative piece of research. I really enjoyed the opportunity to conduct this qualitative study and have learnt many useful skills in the process.

### *Main Research Project*

I knew from the start of training that I wanted to complete my main research project in the area of Clinical Neuropsychology. I met with Dr Simon Gerhand, Consultant Clinical Neuropsychologist in Bristol, to discuss potential ideas. Together we developed a project idea focussing on depressive rumination post-head injury and its impact on cognitive functioning and quality of life. A number of meetings were scheduled with Dr Gerhand and Professor Paul Salkovskis in which the idea was further developed.

During the summer of the first year I piloted the project procedure on a number of patients. Dr Gerhand was very helpful in providing access to willing volunteers and assessment materials. I also met with a number of day centre managers from the brain injury charity Headway, located across Bath, Bristol and Wiltshire, to gauge interest.

Unfortunately, as time progressed it became clear to me that the project would not be feasible within the time frame; primarily it would be difficult to recruit enough volunteers meeting the stringent inclusion/exclusion criteria. I initiated a meeting with both Dr Gerhand and Professor Salkvoskis to discuss my concerns and it was agreed that the project, on reflection, would be unfeasible in the time available. This experience taught me the importance of considering feasibility of a project early on in the research process. I had to make an assertive decision to end the project, despite the significant amount of effort already invested; this was a difficult yet important decision allowing me time to develop a new project idea.

From this point I met with the course team to decide the next course of action. I was aware of another Clinical Neuropsychologist in the area (Dr Leon Dysch) who was keen to co-develop a research project investigating psychological factors in Parkinson's Disease. Through a series of meetings between myself, Dr Dysch and Professor Salkovskis I developed a project proposal, focussing primarily on evaluating the extent of health anxiety in patients with Parkinson's Disease and the impact of health anxiety on psychological distress and quality of life. Initial conversations were also had around the relative contribution of another psychological construct, intolerance of uncertainty (IoU). Although not a primary focus, IoU remained a factor of interest in the final project.

During the beginning of the second year I spent a significant amount of time building links with local Movement Disorder and Neurology centres; this involved several meetings with consultant physicians and attendance at regular team meetings. On reflection, this time invested in the early months of the project paid off. I was able to form good relationships with the teams who were extremely helpful throughout the course of the research in identifying and referring eligible participants.

Seeking ethical approval for the project was a lengthy and sometimes complicated process. I had completed an NHS ethics application prior to training so knew that it could take a long time to complete and that it was important to factor this in. I was also aware of several trainee clinical psychologists in the previous cohort who had

experienced difficulties with recruitment. I therefore ensured from the outset that I considered several potential recruitment sites, both NHS and third sector organisations (Parkinson's UK).

The course provided minimal teaching on applying for NHS ethics approval, although some useful information was provided in the programme handbook. I can imagine this would have been a challenge for individuals who were new to the process. I found the REC manager was an invaluable resource, particularly as the process of submission changed part way through applying. The process of attending a REC meeting and pitching my research proposal to the panel was a useful learning experience.

My main project was ambitious and I was aware from the outset that a large amount of time would need to be invested into the data collection phase of the research. Indeed, each participant needed to be seen individually for a minimum of one hour (87 hours, excluding travel time). Participants were located across BANES and Wiltshire. Although tiring at times, I thoroughly enjoyed meeting participants and I feel I have gained valuable skills in conducting structured interviews and cognitive assessment within a research context. On reflection, it may have been useful to have requested the support of an Assistant Psychologist or Research Assistant.

### **Service User Consultation**

Patients with Parkinson's Disease were consulted during the piloting phase of the main research project. Their feedback regarding the experimental design was important in ensuring that all tasks could be administered in a timely and efficient manner and did not cause excessive fatigue or psychological distress.

Unfortunately I was unable to involve service users in the development of my service improvement project. On reflection, it would appear that if service user feedback was to be effectively incorporated into the design of the research there would have needed to be consultation at a much earlier stage. On reflection, it occurred to me that it may have been helpful for service users to have been invited to the research fair during the first year of training. This would have allowed for

conversations between local psychologists, training psychologists and service users regarding potential research ideas. This is something that I intend to feedback to the Programme.

I am aware that the Bath Programme is working to increase service user involvement in the development of the programme; this includes incorporating service users in teaching as well as getting their input on the admissions process and programme curriculum. It would be helpful to incorporate service users in programme research and for the course to continue building links with local service user groups.

### **Case Studies**

The work of the clinical psychologist is underpinned by the ability to apply psychological theory to practice. It requires the therapist to be flexible in applying their knowledge to best suit the needs of the client and to monitor and reflect on the progress of therapy. Completion of case studies throughout the course of training has been very useful in allowing me to demonstrate these clinical competencies. I have been able to complete case studies on a range of psychological difficulties, including PTSD, Blood-Injury and Injection (BII) phobia, GAD and OCD. Each case study involved the collection of regular outcome data with two studies utilising a single case experimental design. No statistical methods were used to analyse the data; however on reflection statistical tests such as the calculation of reliable and clinically significant change would have been useful in adding to the methodological rigor. The course requirement that case reports demonstrate heuristic value encouraged me to choose interesting and novel cases to write-up. These cases have contributed to the current evidence base and I have been able to disseminate the findings of these reports through conference presentations.

### **Outcomes of Research**

I presented two case study poster presentations at the BABCP conference 2014, one of which was commended in the Excellence Awards. Further, my Service Improvement Project was presented at the European Cystic Fibrosis Conference in Gothenburg, Sweden 2014.

I recently submitted abstracts for two further pieces of research to the upcoming BABCP conference 2015; both have been accepted. I plan to write up all my projects for submission to peer-review journals.

### **Future Aspirations**

I will endeavour to continue conducting research and contributing to the literature on completion of doctoral training. I feel that my experiences developing and conducting research has helped me establish skills as a scientist-practitioner. As clinical psychologists, we are unique in having received advanced training in research design and development; these are valuable skills to take and share with future teams and colleagues.

In the current economic climate, where NHS services are constantly being squeezed, and increasing pressures and demands are being placed on clinicians to produce outcomes, the opportunity and funding for research and service development is challenged. It will be important to be mindful of these challenges from the outset and to think of ways of ensuring that I can remain research active in future job roles. Indeed, it is during these times of increased pressure and cuts to funding that research and service evaluation are key. They allow services to take a step back and to think about how best to use resources to ensure efficient and effective running of services.

I hope to maintain links with the programme, previous supervisors and to link in with local research networks. I hope to continue conducting research, audit and evaluation to produce service level change. As a qualified clinical psychologist I would be keen to supervise other trainee clinical psychologists and assistant psychologists in carrying out research.

The clinical doctorate has provided opportunities to attend and have work presented at both national and international conferences, to share my experiences with other researchers and practitioners in the field, to acquire new knowledge and demonstrate theory-practice links. I hope to continue this post-qualifying.



## **Acknowledgements**

I would like to express my appreciation to my main project supervisor Professor Paul Salkovskis who has been an inspirational mentor over the past three years. His knowledge and expertise have been invaluable and his dedication to ensuring the success of his trainees is highly commendable.

I would also like to express my thanks to my clinical tutor, Dr Lorna Hogg, whose kind and compassionate approach has been greatly appreciated, particularly during challenging times on clinical training. Her words of encouragement and willingness to listen have not gone unnoticed.

I would like to thank all my other project supervisors: Dr James Gregory, Dr Kate Rimes, Dr Catherine Butler and Dr Jo Daniels for their expert advice and guidance. I would like to thank my field supervisor, Dr Leon Dysch and collaborator to the project, Dr Robin Fackrell, for their support with my main project as well as the many individuals with Parkinson's Disease who participated. Indeed, without their input my main project would not have been possible.

Finally I would like to thank my father, for his generosity in taking the time to read and provide feedback on earlier versions of this manuscript and last but not least my husband, Robert, whose unwavering support and faith in me has been invaluable.

## **Appendix A: Instructions for authors for Critical Literature Review**

### **Clinical Psychology Review**

#### **Use of word processing software**

It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word processor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier:

<http://www.elsevier.com/guidepublication>). Note that source files of figures, tables and text graphics will be required whether or not you embed your figures in the text. See also the section on Electronic artwork. To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

#### **Article structure**

Manuscripts should be prepared according to the guidelines set forth in the Publication Manual of the American Psychological Association (6th ed., 2009). Of note, section headings should not be numbered. Manuscripts should ordinarily not exceed 50 pages, including references and tabular material. Exceptions may be made with prior approval of the Editor in Chief. Manuscript length can often be managed through the judicious use of appendices. In general the References section should be limited to citations actually discussed in the text. References to articles solely included in meta-analyses should be included in an appendix, which will appear in the on line version of the paper but not in the print copy. Similarly, extensive Tables describing study characteristics, containing material published elsewhere, or presenting formulas and other technical material should also be included in an

appendix. Authors can direct readers to the appendices in appropriate places in the text.

It is authors' responsibility to ensure their reviews are comprehensive and as up to date as possible (at least through the prior calendar year) so the data are still current at the time of publication. Authors are referred to the PRISMA Guidelines (<http://www.prisma-statement.org/statement.htm>) for guidance in conducting reviews and preparing manuscripts. Adherence to the Guidelines is not required, but is recommended to enhance quality of submissions and impact of published papers on the field.

### *Appendices*

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

### **Essential title page information**

*Title.* Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible. Note: The title page should be the first page of the manuscript document indicating the author's names and affiliations and the corresponding author's complete contact information.

*Author names and affiliations.* Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name, and, if available, the e-mail address of each author within the cover letter.

*Corresponding author.* Clearly indicate who is willing to handle correspondence at all stages of refereeing and publication, also post-publication. Ensure that telephone and fax numbers (with country and area code) are provided in addition to the e-mail address and the complete postal address.

*Present/permanent address.* If an author has moved since the work described in the article was done, or was visiting at the time, a "Present address" (or "Permanent address") may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

*Abstract* A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone. References should therefore be avoided, but if essential, they must be cited in full, without reference to the reference list.

### **Graphical abstract**

Although a graphical abstract is optional, its use is encouraged as it draws more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of  $531 \times 1328$  pixels (h  $\times$  w) or proportionally more. The image should be readable at a size of  $5 \times 13$  cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. See <http://www.elsevier.com/graphicalabstracts> for examples. Authors can make use of Elsevier's Illustration and Enhancement service to ensure the best presentation of their images and in accordance with all technical requirements: Illustration Service.

### **Highlights**

Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point). See <http://www.elsevier.com/highlights> for examples.

## **Keywords**

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

## **Abbreviations**

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

## **Acknowledgements**

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

## **Footnotes**

Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors can build footnotes into the text, and this feature may be used. Otherwise, please indicate the position of footnotes in the text and list the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

## **Electronic artwork**

### *General points*

- Make sure you use uniform lettering and sizing of your original artwork.
- Embed the used fonts if the application provides that option.
- Aim to use the following fonts in your illustrations: Arial, Courier, Times New Roman, Symbol, or use fonts that look similar.
- Number the illustrations according to their sequence in the text.

- Use a logical naming convention for your artwork files.
- Provide captions to illustrations separately.
- Size the illustrations close to the desired dimensions of the published version.
- Submit each illustration as a separate file. A detailed guide on electronic artwork is available on our website:

<http://www.elsevier.com/artworkinstructions>.

You are urged to visit this site; some excerpts from the detailed information are given here.

### *Formats*

If your electronic artwork is created in a Microsoft Office application (Word, PowerPoint, Excel) then please supply 'as is' in the native document format. Regardless of the application used other than Microsoft Office, when your electronic artwork is finalized, please 'Save as' or convert the images to one of the following formats (note the resolution requirements for line drawings, halftones, and line/halftone combinations given below): EPS (or PDF): Vector drawings, embed all used fonts. TIFF (or JPEG): Color or grayscale photographs (halftones), keep to a minimum of 300 dpi. TIFF (or JPEG): Bitmapped (pure black & white pixels) line drawings, keep to a minimum of 1000 dpi. TIFF (or JPEG): Combinations bitmapped line/half-tone (color or grayscale), keep to a minimum of 500 dpi.

Please do not:

- Supply files that are optimized for screen use (e.g., GIF, BMP, PICT, WPG); these typically have a low number of pixels and limited set of colors;
- Supply files that are too low in resolution;
- Submit graphics that are disproportionately large for the content.

### *Color artwork*

Please make sure that artwork files are in an acceptable format (TIFF (or JPEG), EPS (or PDF), or MS Office files) and with the correct resolution. If, together with your accepted article, you submit usable color figures then Elsevier will ensure, at no additional charge, that these figures will appear in color online (e.g., ScienceDirect and other sites) regardless of whether or not these illustrations are reproduced in color in the printed version. For color reproduction in print, you will receive

information regarding the costs from Elsevier after receipt of your accepted article. Please indicate your preference for color: in print or online only. For further information on the preparation of electronic artwork, please see <http://www.elsevier.com/artworkinstructions>. Please note: Because of technical complications that can arise by converting color figures to 'gray scale' (for the printed version should you not opt for color in print) please submit in addition usable black and white versions of all the color illustrations.

### *Figure captions*

Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (not on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

### **Tables**

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules.

### **References**

Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 1-4338-0559-6, copies of which may be ordered from <http://books.apa.org/books.cfm?id=4200067> or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3E 8LU, UK. Details concerning this referencing style can also be found at <http://humanities.byu.edu/linguistics/Henrichsen/APA/APA01.html>

### *Citation in text*

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full.

Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

### *Web references*

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

### *References in a special issue*

Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue. Reference management software Most Elsevier journals have a standard template available in key reference management packages. This covers packages using the Citation Style Language, such as Mendeley (<http://www.mendeley.com/features/reference-manager>) and also others like EndNote (<http://www.endnote.com/support/enstyles.asp>) and Reference Manager (<http://refman.com/support/rmstyles.asp>). Using plug-ins to word processing packages which are available from the above sites, authors only need to select the appropriate journal template when preparing their article and the list of references and citations to these will be formatted according to the journal style as described in this Guide. The process of including templates in these packages is constantly ongoing. If the journal you are looking for does not have a template available yet, please see the list of sample references and citations provided in this Guide to help you format these according to the journal style. If you manage your research with Mendeley Desktop, you can easily install the reference style for this journal by clicking the link below: <http://open.mendeley.com/use-citation-style/clinical-psychology-review> When preparing your manuscript, you will then be able to select



this style using the Mendeley plugins for Microsoft Word or LibreOffice. For more information about the Citation Style Language, visit <http://citationstyles.org>.

### **Reference style**

References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters "a", "b", "c", etc., placed after the year of publication. References should be formatted with a hanging indent (i.e., the first line of each reference is flush left while the subsequent lines are indented).

Examples:

*Reference to a journal publication:* Van der Geer, J., Hanraads, J. A. J., & Lupton R. A. (2000). The art of writing a scientific article. *Journal of Scientific Communications*, 163, 51-59. *Reference to a book:* Strunk, W., Jr., & White, E. B. (1979). *The elements of style*. (3rd ed.). New York: Macmillan, (Chapter 4).

*Reference to a chapter in an edited book:* Mettam, G. R., & Adams, L. B. (1994). How to prepare an electronic version of your article. In B.S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281-304). New York: E-Publishing Inc.

### **Video data**

Elsevier accepts video material and animation sequences to support and enhance your scientific research. Authors who have video or animation files that they wish to submit with their article are strongly encouraged to include links to these within the body of the article. This can be done in the same way as a figure or table by referring to the video or animation content and noting in the body text where it should be placed. All submitted files should be properly labeled so that they directly relate to the video file's content. In order to ensure that your video or animation material is directly usable, please provide the files in one of our recommended file formats with a preferred maximum size of 150 MB. Video and animation files supplied will be published online in the electronic version of your article in Elsevier Web products, including ScienceDirect: <http://www.sciencedirect.com>. Please supply 'stills' with your files: you can choose any frame from the video or animation or make a separate image. These will be used instead of standard icons and will personalize the link to your video data. For more detailed instructions please visit our video instruction

pages at <http://www.elsevier.com/artworkinstructions>. Note: since video and animation cannot be embedded in the print version of the journal, please provide text for both the electronic and the print version for the portions of the article that refer to this content.

### **AudioSlides**

The journal encourages authors to create an AudioSlides presentation with their published article. AudioSlides are brief, webinar-style presentations that are shown next to the online article on ScienceDirect. This gives authors the opportunity to summarize their research in their own words and to help readers understand what the paper is about. More information and examples are available at <http://www.elsevier.com/audioslides>. Authors of this journal will automatically receive an invitation e-mail to create an AudioSlides presentation after acceptance of their paper.

### **Supplementary material**

Elsevier accepts electronic supplementary material to support and enhance your scientific research. Supplementary files offer the author additional possibilities to publish supporting applications, highresolution images, background datasets, sound clips and more. Supplementary files supplied will be published online alongside the electronic version of your article in Elsevier Web products, including ScienceDirect: <http://www.sciencedirect.com>. In order to ensure that your submitted material is directly usable, please provide the data in one of our recommended file formats. Authors should submit the material in electronic format together with the article and supply a concise and descriptive caption for each file. For more detailed instructions please visit our artwork instruction pages at <http://www.elsevier.com/artworkinstructions>.

### **Submission checklist**

The following list will be useful during the final checking of an article prior to sending it to the journal for review. Please consult this Guide for Authors for further details of any item. Ensure that the following items are present:

One author has been designated as the corresponding author with contact details:

- E-mail address
- Full postal address

All necessary files have been uploaded, and contain:

- Keywords
- All figure captions
- All tables (including title, description, footnotes)

Further considerations

- Manuscript has been 'spell-checked' and 'grammar-checked'
- References are in the correct format for this journal
- All references mentioned in the Reference list are cited in the text, and vice versa
- Permission has been obtained for use of copyrighted material from other sources (including the Internet) Printed version of figures (if applicable) in color or black-and-white
- Indicate clearly whether or not color or black-and-white in print is required.
- For reproduction in black-and-white, please supply black-and-white versions of the figures for printing purposes. For any further information please visit our customer support site at <http://support.elsevier.com>.

## **Appendix B: Instructions for authors for Service Improvement Project**

### **Journal of Cystic Fibrosis**

#### **Your Paper Your Way**

We now differentiate between the requirements for new and revised submissions. You may choose to submit your manuscript as a single Word or PDF file to be used in the refereeing process. Only when your paper is at the revision stage, will you be requested to put your paper in to a 'correct format' for acceptance and provide the items required for the publication of your article. To find out more, please visit the Preparation section below.

*Journal of Cystic Fibrosis* publishes original scientific articles, editorials, case reports, short communications and other information relevant to cystic fibrosis and is published six times a year. Papers are accepted on the understanding that they have not been published, and are not being considered for publication elsewhere and are subject to editorial revision.

#### **Original articles**

Original research papers should contain no more than 3,000 words plus no more than 5 figures or tables in total and 30 references. The abstract should consist of 4 paragraphs, labelled Background, Methods, Results, and Conclusions.

#### **Review articles**

Review papers should be authoritative, well referenced reviews of a relevant subject and should not contain more than 5,000 words, and 30 references with no more than six figures or tables.

#### **Letters**

Headings should not be used in a letter; no abstract or keywords are required. The text should be no more than 800 words; there should be a maximum of 5 references and one table or figure may be included.

#### **Correspondence**

Short articles relating to papers recently published in the Journal, or containing brief reports of unusual or preliminary findings. Maximum length 400 words, one table or figure and a maximum of 10 references.

#### **Editorials**

These tend to be invited papers but unsolicited editorials are welcome. There are no abstract, keywords or section headings.

## **Short Communications**

1,200 words plus no more than 3 figures or tables in total 20 references.

## **Case Reports**

These must be carefully documented and must be of importance because they illustrate or describe unusual features or have important therapeutic implications. Maximum length 1200 words, no more than a page and a half in length and a maximum of 1 table or figure. Case reports do not require a structured abstract and should include no more than 5 references.

## **Short Communication**

1,200 words plus no more than 3 figures or tables in total 20 references Page charges  
This journal has no page charges.

## **BEFORE YOU BEGIN**

### **Ethics in publishing**

For information on Ethics in publishing and Ethical guidelines for journal publication see <http://www.elsevier.com/publishingethics> and <http://www.elsevier.com/journal-authors/ethics>.

Work on human beings that is submitted to Respiratory Medicine should comply with the principles laid down in the Declaration of Helsinki; Recommendations guiding physicians in biomedical research involving human subjects. Adopted by the 18th World Medical Assembly, Helsinki, Finland, June 1964, amended by the 29th World Medical Assembly, Tokyo, Japan, October 1975, the 35th World Medical Assembly, Venice, Italy, October 1983, and the 41st World Medical Assembly, Hong Kong, September 1989. The manuscript should contain a statement that the work has been approved by the appropriate ethical committees related to the institution(s) in which it was performed and that subjects gave informed consent to the work. Studies involving experiments with animals must state that their care was in accordance with institution guidelines. Patients' and volunteers' names, initials, and hospital numbers should not be used.

### **Conflict of interest**

All authors must disclose any financial and personal relationships with other people or organizations that could inappropriately influence (bias) their work. Examples of potential conflicts of interest include employment, consultancies, stock ownership, honoraria, paid expert testimony, patent applications/registrations, and grants or other funding. If there are no conflicts of interest then please state this: 'Conflicts of interest: none'. See also <http://www.elsevier.com/conflictsofinterest>. Further information and an example of a Conflict of Interest form can be found at:

## **PREPARATION**

### **NEW SUBMISSIONS**

Submission to this journal proceeds totally online and you will be guided stepwise through the creation and uploading of your files. The system automatically converts your files to a single PDF file, which is used in the peer-review process. As part of the Your Paper Your Way service, you may choose to submit your manuscript as a single file to be used in the refereeing process. This can be a PDF file or a Word document, in any format or layout that can be used by referees to evaluate your manuscript. It should contain high enough quality figures for refereeing. If you prefer to do so, you may still provide all or some of the source files at the initial submission. Please note that individual figure files larger than 10 MB must be uploaded separately.

### **References**

There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct.

### **Formatting requirements**

There are no strict formatting requirements but all manuscripts must contain the essential elements needed to convey your manuscript, for example Abstract, Keywords, Introduction, Materials and Methods, Results, Conclusions, Artwork and Tables with Captions. If your article includes any Videos and/or other Supplementary material, this should be included in your initial submission for peer review purposes. Divide the article into clearly defined sections

Figures and tables embedded in text Please ensure the figures and the tables included in the single file are placed next to the relevant text in the manuscript, rather than at the bottom or the top of the file.

### **Cover letter**

Corresponding authors must provide a cover letter which includes statements answering the following questions:

- Has the work been seen and approved by all co-authors?
- How is the work clinically relevant, and how does it add to existing research?

- Have papers closely related to the submitted manuscript been published or submitted for publication elsewhere? If so please provide details. Failure to provide a cover letter addressing each of the questions above will result in the paper being returned to the author. The cover letter must be uploaded as a separate submission item.

### **Essential title page information**

- *Title*. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.

- *Author names and affiliations*. Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lowercase superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.

- *Corresponding author*. Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.
- *Present/permanent address*. If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes. Avoid use of extraneous words such as "study" and "investigation". The title should be given in capital letters (not exceeding 100 letters), and a running title (not exceeding 50 letters) should also be provided. If data from the manuscript have been presented at a meeting, list the full name, date and location of the meeting and reference any previous abstracts in the bibliography.

### **Abstracts**

An abstract of your manuscript, summarizing the content, should be provided. A maximum of 150 words, should be written in a structured manner (for original articles only) since this will be the only part of the article studied by some readers. In original articles, the Abstract should consist of 4 paragraphs, labelled Background, Methods, Results, and Conclusions. They should briefly describe the problem being addressed in the study, how the study was performed and which measurements were carried out, the most relevant results, and what the authors conclude from the results.

## **Keywords**

A list of three to six keywords should be supplied: full instructions are provided when submitting the article online

## **Abbreviations**

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

## **Acknowledgements**

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

## **Units**

Follow internationally accepted rules and conventions: use the international system of units (SI). If other units are mentioned, please give their equivalent in SI.

## **Footnotes**

Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors build footnotes into the text, and this feature may be used. Should this not be the case, indicate the position of footnotes in the text and present the footnotes themselves separately at the end of the article.

## **Artwork**

Electronic artwork

General points

- Make sure you use uniform lettering and sizing of your original artwork.
- Preferred fonts: Arial (or Helvetica), Times New Roman (or Times), Symbol, Courier.
- Number the illustrations according to their sequence in the text. • Use a logical naming convention for your artwork files.
- Indicate per figure if it is a single, 1.5 or 2-column fitting image.
- For Word submissions only, you may still provide figures and their captions, and tables within a single file at the revision stage.



- Please note that individual figure files larger than 10 MB must be provided in separate source files. A detailed guide on electronic artwork is available on our website: <http://www.elsevier.com/artworkinstructions>. You are urged to visit this site; some excerpts from the detailed information are given here. Formats Regardless of the application used, when your electronic artwork is finalized, please 'save as' or convert the images to one of the following formats (note the resolution requirements for line drawings, halftones, and line/halftone combinations given below): EPS (or PDF): Vector drawings. Embed the font or save the text as 'graphics'. TIFF (or JPG): Color or grayscale photographs (halftones): always use a minimum of 300 dpi. TIFF (or JPG): Bitmapped line drawings: use a minimum of 1000 dpi. TIFF (or JPG): Combinations bitmapped line/half-tone (color or grayscale): a minimum of 500 dpi is required.

Please do not:

- Supply files that are optimized for screen use (e.g., GIF, BMP, PICT, WPG); the resolution is too low.
- Supply files that are too low in resolution.
- Submit graphics that are disproportionately large for the content. Color artwork Please make sure that artwork files are in an acceptable format (TIFF (or JPEG), EPS (or PDF), or MS Office files) and with the correct resolution. If, together with your accepted article, you submit usable color figures then Elsevier will ensure, at no additional charge, that these figures will appear in color online (e.g., ScienceDirect and other sites) regardless of whether or not these illustrations are reproduced in color in the printed version. For color reproduction in print, you will receive information regarding the costs from Elsevier after receipt of your accepted article. Please indicate your preference for color: in print or online only. For further information on the preparation of electronic artwork, please see <http://www.elsevier.com/artworkinstructions>.

## Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules.

## References

Manuscripts should use the Vancouver style for references.

### *Citation in text*

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

### *Reference links*

Increased discoverability of research and high quality peer review are ensured by online links to the sources cited. In order to allow us to create links to abstracting and indexing services, such as Scopus, CrossRef and PubMed, please ensure that data provided in the references are correct. Please note that incorrect surnames, journal/book titles, publication year and pagination may prevent link creation. When copying references, please be careful as they may already contain errors. Use of the DOI is encouraged.

### *Web references*

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

### *Conflict of interest disclosure*

The Journal of Cystic Fibrosis has adopted the Conflict of Interest Disclosure form provided by the International Committee of Medical Journal Editors (ICMJE) and requests authors to complete it during the submission process; a copy of the form can be found here <http://www.icmje.org/conflicts-of-interest/>

### *References in a special issue*

Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

### *Reference management software*

Most Elsevier journals have a standard template available in key reference management packages. This covers packages using the Citation Style Language, such as Mendeley (<http://www.mendeley.com/features/reference-manager>) and also others like EndNote (<http://www.endnote.com/support/enstyles.asp>) and Reference Manager

Using plug-ins to word processing packages which are available from the above sites, authors only need to select the appropriate journal template when preparing their article and the list of references and citations to these will be formatted according to the journal style as described in this Guide. The process of including templates in these packages is constantly ongoing. If the journal you are looking for does not have a template available yet, please see the list of sample references and citations provided in this Guide to help you format these according to the journal style. If you manage your research with Mendeley Desktop, you can easily install the reference style for this journal by clicking the link below: <http://open.mendeley.com/use-citation-style/journal-of-cystic-fibrosis> When preparing your manuscript, you will then be able to select this style using the Mendeley plugins for Microsoft Word or LibreOffice. For more information about the Citation Style Language, visit <http://citationstyles.org>.

### *Reference formatting*

There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct. If you do wish to format the references yourself they should be arranged according to the following examples:

### *Reference style*

Text: Indicate references by number(s) in square brackets in line with the text. The actual authors can be referred to, but the reference number(s) must always be given.  
List: Number the references (numbers in square brackets) in the list in the order in which they appear in the text.

Examples:

### *Reference to a journal publication:*

[1] Van der Geer J, Hanraads JAJ, Lupton RA. The art of writing a scientific article. J Sci Commun 2010;163:51–9.

### *Reference to a book:*

[2] Strunk Jr W, White EB. The elements of style. 4th ed. New York: Longman; 2000.

### *Reference to a chapter in an edited book:*

[3] Mettam GR, Adams LB. How to prepare an electronic version of your article. In: Jones BS, Smith RZ, editors. Introduction to the electronic age, New York: E-

Publishing Inc; 2009, p. 281–304. Note shortened form for last page number. e.g., 51–9, and that for more than 6 authors the first 6 should be listed followed by 'et al.' For further details you are referred to 'Uniform Requirements for Manuscripts submitted to Biomedical Journals' (J Am Med Assoc 1997;277:927–34)

(see also [http://www.nlm.nih.gov/bsd/uniform\\_requirements.html](http://www.nlm.nih.gov/bsd/uniform_requirements.html)).

### **Submission checklist**

The following list will be useful during the final checking of an article prior to sending it to the journal for review. Please consult this Guide for Authors for further details of any item.

Ensure that the following items are present:

One author has been designated as the corresponding author with contact details:

- E-mail address
- Full postal address

All necessary files have been uploaded, and contain:

- Keywords
- All figure captions
- All tables (including title, description, footnotes)

Further considerations

- Manuscript has been 'spell-checked' and 'grammar-checked'
- All references mentioned in the Reference list are cited in the text, and vice versa
- Permission has been obtained for use of copyrighted material from other sources (including the Internet) Printed version of figures (if applicable) in color or black-and-white
- Indicate clearly whether or not color or black-and-white in print is required.
- For reproduction in black-and-white, please supply black-and-white versions of the figures for printing purposes. For any further information please visit our customer support site at <http://support.elsevier.com>. Additional Information Authors should use the 'Track Changes' option when revising their manuscripts, so that any changes made to the original submission are easily visible to the Editors. Those revised manuscripts upon which the changes are not clear may be returned to the author. Specific comments made in the Author Comments in response to referees' comments must be organised clearly. For example, use the same numbering system as the

referee, or use 2 columns of which one states the comment and the other the response.

## Appendix C: Information relevant to ethical review (Service Improvement Project)

This study was approved by the University Hospitals Bristol Questionnaire, Interview and Service (QIS) Committee on 7<sup>th</sup> August 2013. Their approval process means that a reference number was not assigned, however my contact was Tony Watkin, Patient Experience Lead (Engagement and Involvement) at the University Hospitals Bristol NHS Foundation Trust.

The Service Improvement Project received approval from The University of Bath Research Ethics Committee (reference number 13-117). In the absence of a letter, a copy of an email confirming ethical approval is copied below:



## **Appendix D: Service recommendations (Service Improvement Project)**

### **Service recommendations**

The following recommendations for service improvement were proposed; these were based on the results of the thematic analysis:

#### *1) Preparatory materials including reference to the medical, psychosocial and practical aspects of admission*

It is recommended that parents are provided with preparatory materials prior to admission, with particular reference made to the medical management of their child's condition as well as the psychosocial and practical implications. Parents should be provided with advice on how to prepare their child for hospitalisation, what to expect from the hospital experience and information pertaining to the treatment and expected outcomes. These materials should be provided in sufficient time to allow parents to review the information and ask for clarity on aspects that are unclear. Preparatory materials are already in use in other countries (e.g., United States); please see [www.choa.org](http://www.choa.org) for an example brochure.

#### *2) Pre-admission visit to the ward*

It is recommended that parents are given the opportunity to have a pre-admission visit to the ward in order to build familiarity with the setting and decrease anxiety. Alternatively, this information could be presented in the form of a virtual tour posted on the departmental or Trust website.

#### *3) Increasing the visibility of the paediatric CF team*

It is recommended that parents are made aware, prior to admission, that although their child will not be in the direct care of the CF team whilst on the ward, the CF team will be kept informed of their child's progress through their attendance at weekly team meetings. It is recommended that a representative of the CF team takes an active role in attending weekly ward rounds to increase visibility of the team on the ward and answer any specific questions or concerns that parents may have.

*4) Increasing awareness of parental role on the ward and improving communication*

It is recommended that ward staff are made aware of the active role parent's take in the day-to-day management of their child's condition. Staff should discuss with parents to what extent they wish to be involved in their child's care and facilitate any contribution, where possible, through effective support and communication.



## **Appendix E: Feedback to service (Service Improvement Project)**

### **Feedback to service**

The themes arising from the study were presented to the CF team as part of the monthly team meeting. Present were the consultant physician, dietician, senior nurse, team psychologist and physiotherapist. Recommendations were presented as preliminary ideas to then be elaborated. It was unanimously agreed that a preparatory material should be created and distributed to parents prior to admission. It was suggested by a number of team members that each specialty could contribute to the final document. There was discussion regarding the best time to distribute this; the general consensus was at a point in which hospitalisation for IV antibiotics was highly probable (i.e., when two courses of oral anti-biotics have proved unsuccessful).

The team felt that there would be difficulty in arranging organised ward visits prior to admission due to challenges surrounding feasibility and confidentiality. However, it was agreed that there would be value in the service creating a virtual tour of the ward which could be uploaded onto the departmental or Trust website. The team physician noted the need to consult management regarding the implementation of this.

Through discussion it was established there was certainly merit in a member of the CF team joining select ward rounds to improve team visibility. Further it would provide a point of contact for parents to raise specific questions or concerns they may have. It was highlighted that some parents reported feeling unable to discuss their concerns with members of the generic ward team.

Finally, the CF team were in agreement with the need to include parents, where possible, in their child's care whilst on the ward. The team raised awareness to the practical and ethical factors impacting on this and subsequently highlighted the need for staff to be more explicit prior to admission about the extent to which parents would be able to exert their role on the ward, thus setting realistic expectations. The need for more open and effective staff-patient communication in facilitating this

process was discussed. Brief communication skills training to ward staff was proposed by the CF psychologist. The nursing staff suggested using 'micro-teaches' (10 minute teaching slots) or a 'regional study day' as potential forums for this.

### **Further actions required**

- It was agreed that the CF Consultant Physician would speak with senior management regarding the development and implementation of a virtual tour on the departmental or Trust website.
- The team psychologist agreed to develop a brochure in collaboration with all members of the CF team addressing the pre-hospitalisation information needs of parents.
- The CF Consultant Physician agreed to liaise with both the CF and ward teams to set up joint weekly ward rounds.
- The team psychologist agreed to liaise with the ward nursing team regarding the implementation of a brief communication skills training session.

## **Appendix F: Instructions for authors for Main Research Project**

### **Journal of Parkinson's Disease**

#### **PREPARATION OF MANUSCRIPTS**

##### **Research Reports**

##### **Organization and style of presentation**

Manuscripts must be written in English. Authors whose native language is not English are recommended to seek the advice of a native English speaker, if possible, before submitting their manuscripts.

Manuscripts should be double spaced throughout with wide margins (2.5cm or 1 in), including the abstract and references. Every page of the manuscript, including the title page, references, tables, etc., should include a page number centered at the bottom.

Manuscripts should be organized in the following order with headings and subheadings typed on a separate line, without indentation.

##### **Title page**

- Title (should be clear, descriptive and concise).
- Full name(s) of author(s).
- Full affiliation(s). Delineate affiliations with lowercase letters.
- Present address of author(s), if different from affiliation.
- Running title (45 characters or less, including spaces).
- Complete correspondence address, including telephone number, fax number and e-mail address.

Leave the author information blank if double-blind peer review is wished for, but do include the information in the submission letter to the editor.

##### **Abstract and Keywords**

The abstract for research papers should follow the “structured abstract” format:

**BACKGROUND:**

**OBJECTIVE:**

**METHODS:**

**RESULTS:**

**CONCLUSIONS:**

The abstract should try to be no longer than 250 words.

For other papers such as Reviews, the abstract should be clear, descriptive, and self-explanatory, and no longer than 250 words.

Include a list of 4-10 keywords. These keywords should be terms from the MeSH database.

### **Introduction**

### **Materials and Methods**

There is no word limit to the materials and methods section, as the journal's policy is that methodological rigour and reproducibility is of great importance.

### **Results**

### **Discussion**

### **Acknowledgments including sources of support**

### **Conflict of Interest**

If there is no conflict of interest to declare, do still include this section and insert "The authors have no conflict of interest to report".

### **References**

- Click [here](#) to download the EndNote reference style file for JPD articles.
- Place citations as numbers in square brackets in the text. All publications cited in the text should be presented in a list of references following the text of the manuscript. Only articles published or accepted for publication should be listed in the reference list. Submitted articles can be listed in the text as (Author(s), unpublished data).
- All authors should be listed in the reference list.
- References should be listed in the order of appearance in the following style:

[1] Alzheimer Research Forum, Drugs in Clinical Trials: AAB-001, <http://www.alzforum.org/drg/drc/detail.asp?id=101>, Last updated May 29,

2007, Accessed on January 29, 2008.

[2] Smith MA (2006) Oxidative stress and iron imbalance in Alzheimer disease: how rust became the fuss! In Alzheimer's Disease: A Century of Scientific and Clinical Research, Perry G, Avila J, Kinoshita J, Smith MA, eds. IOS Press, Amsterdam, pp. 305-308.

[3] Hara H, Monsonogo A, Yuasa K, Adachi K, Xiao X, Takeda S, Takahashi K, Weiner HL, Tabira T (2004) Development of a safe oral Abeta vaccine using recombinant adeno-associated virus vector for Alzheimer's disease. J Alzheimers Dis 6, 483-488.

[4] Paxinos G, Watson C (1986) The Rat Brain in Stereotaxic Coordinates, Academic Press, Sydney.

[5] Zhu X, Perry G, Smith MA (2004) Two hits and you're out? A novel mechanistic hypothesis of Alzheimer disease, Alzheimer Research Forum, <http://www.alzforum.org/res/adh/cur/zhu/default.asp>, Posted 23 October 2004, Accessed January 29, 2008.

## Tables

Number according to their sequence in the text. The text should include references to all tables.

Provide each table on a separate page of the manuscript after the references.

Include a brief and self-explanatory title with any explanations essential to the understanding of the table given in footnotes at the bottom of the table.

Vertical lines should not be used to separate columns. Leave some extra space between the columns instead.

## Figures

Number the figures according to their sequence in the text. The text should include references to all figures.

For the file formats of the figures please take the following into account:

- Line art should have a minimum resolution of 1200 dpi, save as EPS or TIFF.
- Do not use faint lines and/or lettering and check that all lines and lettering within the figures are legible at final size.
- All lines should be at least 0.1 mm (0.3 pt) wide.
- Vector graphics containing fonts must have the fonts embedded in the files.

- Grayscales (incl photos) should have a minimum resolution of 300 dpi, or 600 dpi for combination art (lettering and images); save as TIFF.
- Do not save figures as JPEG, this format may lose information in the process
- Do not use figures taken from the Internet, the resolution will be too low for printing
- Do not use color in your figures if they are to be printed in black & white, as this will reduce the print quality (note that in software often the default is color, you should change the settings)
- For figures that should be printed in color, please send a CMYK encoded EPS or TIFF

Figures should be designed with the format of JPD in mind and preferable sized as they will appear when printed. A single column of the journal is 77mm and two columns are 165mm.

Figures should be cropped to include the figure only (no blank space).

On figures where a scale is needed, use bar scales to avoid problems if the figure needs to be reduced.

Each illustration should have a brief self-explanatory legend that should be typed separately from the figure in the section of the manuscript following the tables.

### **Supplementary Data**

Supplementary data can be submitted with the manuscript, inserted at the end of the document. Legends should be included for each item. Each supplementary item should not exceed the file size of 10MB. Supplemental videos can also be submitted, and a title and legend should be included as Supplementary Material within the manuscript. Large datasets should be hosted on the author's own or institute's website or in an appropriate database.

## Appendix G: Information relevant to ethical review (Main Research Project)

For all the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.  
Yn eiddo oedwaith ymchwil Cymru a'r enw'n gysylltu gyda'r Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



Wales Research Ethics Committee 2  
6<sup>th</sup> Floor Churchill House  
17 Churchill Way  
Cardiff  
CF10 2TW

Telephone : 02920 376823  
E-mail : [carl.phillips@wales.nhs.uk](mailto:carl.phillips@wales.nhs.uk)  
Website : [www.nres.nhs.uk](http://www.nres.nhs.uk)

3 July 2014

Miss Vera Christina Hughes  
Clinical Psychologist in Training  
Taunton and Somerset Foundation Trust  
University of Bath  
Department of Psychology  
Claverton Down, Bath  
BA2 7AY

Dear Miss Hughes

Study title: Psychological factors in Parkinson's disease  
REC reference: 14/WA/0193  
IRAS project ID: 147683

Thank you for your letter of the 30 June 2014, responding to the Committee's request for further information on the above research and for submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Carl Phillips, [carl.phillips@wales.nhs.uk](mailto:carl.phillips@wales.nhs.uk).

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.
- Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.
- Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.odforum.nhs.uk>.

- Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.
- For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.
- Sponsors are not required to notify the Committee of approvals from host organisations

#### Registration of Clinical Trials

- All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).
- There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.
- To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.
- If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### Ethical review of research sites

##### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Research advertisement]	2	30 June 2014
Covering letter on headed paper [Covering letter on headed paper]	1	31 May 2014
Covering letter on headed paper [Covering letter on headed paper]	2	30 June 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Indemnity form]	1	31 May 2014
IRAS Checklist XML [Checklist_03062014]		03 June 2014
IRAS Checklist XML [Checklist_01072014]		01 July 2014



Letter from sponsor [Letter from sponsor]	1	27 May 2014
Non-validated questionnaire [HAI Parkinson's disease]		
Other [Consent to Contact]	1	31 May 2014
Participant consent form [Participant Consent Form - Controls]	1	31 May 2014
Participant consent form [Participant Consent Form]	1	31 May 2014
Participant information sheet (PIS) [Participant Information Sheet (Patient) Revised]	2	30 June 2014
Participant information sheet (PIS) [Revised Participant Information Sheet (Controls)]	2	30 June 2014
REC Application Form [REC_Form_03082014]		03 June 2014
Research protocol or project proposal [Revised Research Protocol]	2	30 July 2014
Summary CV for student [Vera Hughes CV]	1	30 May 2014
Summary CV for supervisor (student research) [Academic Supervisor 1 CV]	1	30 May 2014
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Flowchart]	1	31 May 2014
Validated questionnaire [UPDRS]		
Validated questionnaire [Hospital Anxiety and Depression Scale]		
Validated questionnaire [Intolerance of uncertainty scale-12]		
Validated questionnaire [Ferrans and Powers]		
Validated questionnaire [Hohn & Yahr and Schwab and England Scales]		

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### **After ethical review**

##### **Reporting requirements**

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

##### **Feedback**

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:  
<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

**14/WA/0193 Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.


Yours sincerely



**Dr I Doull**  
**Chair, Wales Research Ethics Committee 2**  
Email: [carl.phillips@wales.nhs.uk](mailto:carl.phillips@wales.nhs.uk)

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Copied:- Miss V Hughes, [vch23@bath.ac.uk](mailto:vch23@bath.ac.uk)  
Prof P Salkovskis, [p.m.salkovskis@bath.ac.uk](mailto:p.m.salkovskis@bath.ac.uk)  
Dr L Dysch, [leon.dysch@sirona-cic.org.uk](mailto:leon.dysch@sirona-cic.org.uk)  
Prof J Millar, [j.j.millar@bath.ac.uk](mailto:j.j.millar@bath.ac.uk)

<p><b>Dr Andrew Medley</b>  Research Tutor &amp; Clinical Psychologist  Member of Psychology Ethics Committee  Telephone +44 01225 383788  E-mail: A.R.Medley@bath.ac.uk</p>	 <p><b>UNIVERSITY OF BATH</b>  Department of Psychology  Bath BA2 7AY - United Kingdom</p>
--	--

10<sup>th</sup> July 2014

Dear Vera

**Ethics application:** 14-173

**Title of project:** Psychological factors in Parkinson's disease

The Psychology Ethics Committee have considered your ethics proposal for the above study and have given it full ethical approval.

Best wishes with your research.

Dr Andrew Medley  
Research Tutor & Clinical Psychologist  
Psychology Ethics Committee

## Appendix H: Participant Information Sheet

Department of  
**Psychology**



UNIVERSITY OF  
**BATH**

### Participant Information Sheet (Patient)

Psychological factors in Parkinson's disease

#### Invitation to take part in a research project

My name is Vera Hughes. I am a Clinical Psychologist in Training at the Department of Psychology, University of Bath, supervised by Professor Paul Salkovskis. I am currently working in collaboration with Dr Robin Fackrell (Consultant Physician), Dr Leon Dysch (Clinical Psychologist) and the Movement Disorders Team at Bath, conducting research into psychological factors in Parkinson's disease. We would like to invite you to take part.

Before deciding whether or not you would like to take part, we would ask that you read this information sheet which describes why we are doing this research project, and why it would involve you. Your participation in this project is completely voluntary; it is up to you to decide if you would like to take part. Your decision will not affect any treatment or care you are receiving, in any way. Even if you decide to participate in the project you are free to withdraw from it at any time and without giving a reason.

Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

#### Why are we doing this research project?

Parkinson's disease is chronic and disabling condition. It can interfere hugely with a person's life, affecting ones future goals and aspirations. It is understandable therefore that research indicates high levels of anxiety and depression among individuals with Parkinson's disease.

This study aims to further explore individuals' reactions to Parkinson's disease, looking specifically at anxiety relating to health and the impact of this on quality of life and well-being. This research will hopefully point the way forward for better treatment for patients with Parkinson's disease who suffer from emotional distress.

**Why have I been chosen?**

You have been chosen to participate in the study because you have received a diagnosis of Parkinson's disease. About 60 other people with Parkinson's disease will take part in the research.

**Do I have to take part?**

It is up to you to decide whether or not to take part. Your clinician will describe the study and go through this information sheet with you. If you decide to take part, you will be given this information sheet to keep. If you need more time to consider your participation, I can call you (with your permission) at a pre-arranged convenient time. You will still be free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

**What will I be asked to do if I take part?**

I will arrange a research appointment with you, at a time that is convenient. You will be free to choose whether you would like for this to take place at home or at one of the hospital sites (St Martin's Hospital or the Royal United Hospital, Bath). Prior to our appointment I will ask that you complete a short questionnaire pack which will include questions relating to the following topics:

- You quality of life.
- How anxious you are about your health.
- General levels of anxiety and low mood.
- Your physical disability due to having Parkinson's disease.

Completion of the questionnaire measures should take no longer than 35 minutes. You may wish to complete these at home alone, in the company of a friend or relative or bring them along to the research appointment, where I can assist you.

During the research session you will be asked to complete two short tasks designed to evaluate the way your Parkinson's disease is affecting you. One will be looking at your thinking skills and the second will measure your physical strength using what is called a hand grip dynamometer. This requires you to grip a lever and hold it while a measure is taken on a dial. In total the research session should take no more than 1 hour.

On completion of the study, a summary of the findings will be made available to you should you want a copy. The research team would like to offer you £5 towards parking and travelling expenses as a token of our appreciation.

### **Your wellbeing, while participating in the project**

Participating in the study will involve some of your time to fill out questionnaires and tasks and may involve a trip to the hospital to complete these. This process might cause you to feel tired. Filling out questionnaires about low mood and anxiety can sometimes be distressing. If at any time you feel as if you have had enough of the questions, or begin to feel upset by them, please do stop. If you want to return after a break that would be fine, or if you didn't want to do anymore that would be fine also. The top priority is your well-being. If you feel that you'd like to talk over any thoughts you have while filling out the questionnaires, or afterwards, I would be very happy to talk to you about this. If necessary, we can arrange access to support from a qualified Clinical Psychologist and/or your Consultant Physician. If the research team feel especially concerned about your wellbeing, then we will discuss this with you, your medical team and GP in order to determine your preferences and needs for additional support.

### **What are the possible benefits of taking part?**

We cannot promise the study will help you directly but the information collected from you and other participants may help to us to provide better information and advice to people with Parkinson's disease. A further benefit of this type of research will be to inform the application of psychological therapies.

### **Will my taking part in this study be kept confidential?**

Information which is collected about you during the course of the research will be kept confidential and will conform to the Data Protection Act of 1998 with respect to data collection, storage and destruction. This means that all paper-based and electronic information will be locked and password protected with access restricted to study personnel and any information about you will have your name and address removed so that you cannot be identified from it. The Research Governance Sponsor of this study, University of Bath, may monitor or audit this study to ensure that it is being conducted appropriately but your identity will not be revealed.

We hope to report our findings in academic/health related journals and present them to relevant health professionals at meetings and conferences. The findings will also contribute to my Doctorate in Clinical Psychology. You will not be identified in any reports or publications arising from the study.

**Please note:** there may be exceptional circumstances when confidential information may need to be released. For example, if there is reason to believe that there is a risk of significant harm to you or another person. Even in such exceptional cases we will always attempt to obtain your consent before disclosing any information.

**Who is funding this research?**

The research is being funded as part of the researcher's Professional Doctorate in Clinical Psychology at the University of Bath.

**Who has reviewed the study?**

Full NHS ethical approval has been sought for this project (via an NHS Research Ethics Committee), along with local R&D approval from the relevant NHS Trusts and the University of Bath Department of Psychology ethics committee.

**What to do if there is a problem?**

If you have any concerns or wish to complain about any aspect of the way you have been approached or treated as part of this study, you should initially contact myself or my supervisor, Professor Paul Salkovskis. We will do our best to answer your questions (see contact details below). If you remain unhappy and wish to complain formally, you can do this through the Sirona Care and Health Customer Care Services (Details can be obtained from their website).

In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Bath but you may have to pay your legal costs.

**Contact for Further Information**

If you think you might be interested in taking part, or have any questions about the project, please contact me on 07704517743 or by email: [vch23@bath.ac.uk](mailto:vch23@bath.ac.uk). Alternatively, contact Professor Paul Salkovskis (Course and Research Director) on 01225 384350 or by email on: [p.m.salkovskis@bath.ac.uk](mailto:p.m.salkovskis@bath.ac.uk).

Please keep this part of the sheet yourself for reference. Please feel free to ask any questions before you complete the consent form on the following page, and then return the completed consent form to the researcher (Vera Hughes). It will be stored separately from the anonymous information you provide for the research project.

**Thank you for considering taking part and taking time to read this information**

## Appendix I: Consent Form

Department of  
Psychology



UNIVERSITY OF  
**BATH**

### Consent Form

**Title of Project:** Psychological factors in Parkinson's disease

**Name of Researcher:** Vera Hughes, Trainee Clinical Psychologist, supervised by Professor Paul Salkovskis (Course and Research Director) and Dr Leon Dysch (Clinical Psychologist)

**Please initial box**

1. I confirm that I have read and understand the Participant Information Sheet dated 30.06.14 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that data collected during the study, may be looked at by individuals from University of Bath, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.
4. I agree that once I have completed the study, if I lose the capacity of consent, that my data will be retained by the researchers for analysis in an anonymised form
5. I agree to take part in the above study.

☐☐☐☐☐



Name of participant:

Signature:

Date:

Name of researcher:

Signature:

Date:

*1 copy for participant and 1 copy for researcher*

## Appendix J: Questionnaire Measures

Permission to use the MDS-UPDRS was sought from the International Parkinson and Movement Disorder Society. All other questionnaire measures included in this section were freely available online.

### UPDRS Section II

This questionnaire asks you about your experiences of daily living. There are 20 questions. We are trying to be thorough, and some of these questions may therefore not apply to you now or ever. If you do not have the problem, simply mark 0 for NO.

Please read each one carefully and read all answers before selecting the one that best applies to you, **do this by circling the number that corresponds to your chosen response**. We are interested in your average or usual function **over the past week** including today. Some patients can do things better at one time of the day than at others. However, only one answer is allowed for each question, so please mark the answer that best describes what you can do most of the time.

You may have other medical conditions besides Parkinson's disease (PD). Do not worry about separating Parkinson's disease from other conditions. Just answer the question with your best response.

**See next page for questions.**

### 1. SLEEP PROBLEMS

Over the past week, have you had trouble going to sleep at night or staying asleep through the night? Consider how rested you felt after waking up in the morning.

0	No problems.
1	Sleep problems are present but usually do not cause trouble getting a full night of sleep.
2	Sleep problems usually cause some difficulties getting a full night of sleep.
3	Sleep problems cause a lot of difficulties getting a full night of sleep, but I still usually sleep for more than half the night.
4	I usually do not sleep for most of the night.

### 2. DAYTIME SLEEPINESS

Over the past week, have you had trouble staying awake during the daytime?

0	No daytime sleepiness.
1	Daytime sleepiness occurs but I can resist and I stay awake.
2	Sometimes I fall asleep when alone and relaxing. For example, while reading or watching TV.
3	I sometimes fall asleep when I should not. For example, while eating or talking with other people.
4	I often fall asleep when I should not. For example, while eating or talking with other people.

### 3. PAIN AND OTHER SENSATIONS

Over the past week, have you had uncomfortable feelings in your body like pain, aches tingling or cramps?

0	No uncomfortable feelings.
1	I have these feelings. However, I can do things and be with other people without difficulty.
2	These feelings cause some problems when I do things or am with other people.
3	These feelings cause a lot of problems, but they do not stop me from doing things or being with other people.
4	These feelings stop me from doing things or being with other People.

### 4. URINARY PROBLEMS

Over the past week, have you had trouble with urine control? For example, an urgent need to urinate, a need to urinate too often, or urine accidents?

0	No urine control problems.
1	I need to urinate often or urgently. However, these problems do not cause difficulties with my daily activities.
2	Urine problems cause some difficulties with my daily activities. However, I do not have urine accidents.
3	Urine problems cause a lot of difficulties with my daily activities, including urine accidents.
4	I cannot control my urine and use a protective garment or have a bladder tube.

## 5. CONSTIPATION PROBLEMS

Over the past week have you had constipation troubles that cause you difficulty moving your bowels?

0	No constipation.
1	I have been constipated. I use extra effort to move my bowels. However, this problem does not disturb my activities or my being comfortable.
2	Constipation causes me to have some troubles doing things or being comfortable.
3	Constipation causes me to have a lot of trouble doing things or being comfortable. However, it does not stop me from doing anything.
4	I usually need physical help from someone else to empty my bowels.

## 6. LIGHT HEADEDNESS ON STANDING

Over the past week, have you felt faint, dizzy or foggy when you stand up after sitting or lying down?

0	No dizzy or foggy feelings.
1	Dizzy or foggy feelings occur. However, they do not cause me troubles doing things.
2	Dizzy or foggy feelings cause me to hold on to something, but I do not need to sit or lie back down.
3	Dizzy or foggy feelings cause me to sit or lie down to avoid fainting or falling.
4	Dizzy or foggy feelings cause me to fall or faint.

## 7. FATIGUE

Over the past week, have you usually felt fatigued? This feeling is not part of being sleepy or sad

0	No fatigue.
1	Fatigue occurs. However it does not cause me troubles doing things or being with people.
2	Fatigue causes me some troubles doing things or being with people.
3	Fatigue causes me a lot of troubles doing things or being with people. However, it does not stop me from doing anything.
4	Fatigue stops me from doing things or being with people.

## 8. SPEECH

Over the past week, have you had problems with your speech?

0	Not at all (no problems).
1	My speech is soft, slurred or uneven, but it does not cause others to ask me to repeat myself.
2	My speech causes people to ask me to occasionally repeat myself, but not every day.
3	My speech is unclear enough that others ask me to repeat myself every day even though most of my speech is understood.
4	Most or all of my speech cannot be understood.

### 9. SALIVA & DROOLING

Over the past week, have you usually had too much saliva during when you are awake or when you sleep?

0	Not at all (no problems).
1	I have too much saliva, but do not drool.
2	I have some drooling during sleep, but none when I am awake.
3	I have some drooling when I am awake, but I usually do not need tissues or a handkerchief.
4	I have so much drooling that I regularly need to use tissues or a handkerchief to protect my clothes.

### 10. CHEWING AND SWALLOWING

Over the past week, have you usually had problems swallowing pills or eating meals? Do you need your pills cut or crushed or your meals to be made soft, chopped or blended to avoid choking?

0	No problems.
1	I am aware of slowness in my chewing or increased effort at swallowing, but I do not choke or need to have my food specially prepared.
2	I need to have my pills cut or my food specially prepared because of chewing or swallowing problems, but I have not choked over the past week.
3	I choked at least once in the past week.
4	Because of chewing and swallowing problems, I need a feeding tube.

### 11. EATING TASKS

Over the past week, have you usually had troubles handling your food and using eating utensils? For example, do you have trouble handling finger foods or using forks, knives, spoons, chopsticks?

0	Not at all (No problems).
1	I am slow, but I do not need any help handling my food and have not had food spills while eating.
2	I am slow with my eating and have occasional food spills. I may need help with a few tasks such as cutting meat.
3	I need help with many eating tasks but can manage some alone.
4	I need help for most or all eating tasks.

### 12. DRESSING

Over the past week, have you usually had problems dressing? For example, are you slow or do you need help with buttoning, using zippers, putting on or taking off your clothes or jewellery?

0	Not at all (no problems).
1	I am slow but I do not need help.
2	I am slow and need help for a few dressing tasks (buttons, bracelets).
3	I need help for many dressing tasks.
4	I need help for most or all dressing tasks.



### 13. HYGIENE

Over the past week, have you usually been slow or do you need help with washing, bathing, shaving, brushing teeth, combing your hair or with other personal hygiene?

0	Not at all (no problems).
1	I am slow but I do not need any help.
2	I need someone else to help me with some hygiene tasks.
3	I need help for many hygiene tasks.
4	I need help for most or all of my hygiene tasks.

### 14. HANDWRITING

Over the past week, have people usually had trouble reading your handwriting?

0	Not at all (no problems).
1	My writing is slow, clumsy or uneven, but all words are clear.
2	Some words are unclear and difficult to read.
3	Many words are unclear and difficult to read.
4	Most or all words cannot be read.

### 15. DOING HOBBIES AND OTHER ACTIVITIES

Over the past week, have you usually had trouble doing your hobbies or other things that you like to do?

0	Not at all (no problems).
1	I am a bit slow but do these activities easily.
2	I have some difficulty doing these activities.
3	I have major problems doing these activities, but still do most.
4	I am unable to do most or all of these activities.

### 16. TURNING IN BED

Over the past week, do you usually have trouble turning over in bed?

0	Not at all (no problems).
1	I have a bit of trouble turning, but I do not need any help.
2	I have a lot of trouble turning and need occasional help from someone else.
3	To turn over I often need help from someone else.
4	I am unable to turn over without help from someone else.

### 17. TREMOR

Over the past week, have you usually had shaking or tremor?

0	Not at all. I have no shaking or tremor.
1	Shaking or tremor occurs but does not cause problems with any activities.
2	Shaking or tremor causes problems with only a few activities.
3	Shaking or tremor causes problems with many of my daily activities.
4	Shaking or tremor causes problems with most or all activities.

### 18. GETTING OUT OF BED, A CAR, OR A DEEP CHAIR

Over the past week, have you usually had trouble getting out of bed, a car seat, or a deep chair?

0	Not at all (no problems).
1	I am slow or awkward, but I usually can do it on my first try.
2	I need more than one try to get up or need occasional help.
3	I sometimes need help to get up, but most times I can still do it on my own.
4	I need help most or all of the time.

### 19. WALKING AND BALANCE

Over the past week, have you usually had problems with balance and walking?

0	Not at all (no problems).
1	I am slightly slow or may drag a leg. I never use a walking aid.
2	I occasionally use a walking aid, but I do not need any help from another person.
3	I usually use a walking aid (cane, walker) to walk safely without falling. However, I do not usually need the support of another person.
4	I usually use the support of another person's to walk safely without falling.

### 20. FREEZING

Over the past week, on your usual day when walking, do you suddenly stop or freeze as if your feet are stuck to the floor.

0	Not at all (no problems).
1	I briefly freeze but I can easily start walking again. I do not need help from someone else or a walking aid (cane or walker) because of freezing.
2	I freeze and have trouble starting to walk again, but I do not need someone's help or a walking aid (cane or walker) because of freezing.
3	When I freeze I have a lot of trouble starting to walk again and, because of freezing, I sometimes need to use a walking aid or need someone else's help.
4	Because of freezing, most or all of the time, I need to use a walking aid or someone's help.

### Hospital Anxiety and Depression Scale (HADS)

The 14 items below ask about your current mood and anxiety levels. Please read each item below and **place a tick in the box** next to the item that comes closest to how you have been feeling **in the past week**. Don't take too long over your reply; your immediate reaction to each item will probably be more accurate than a long, thought-out response.

1. I feel tense or 'wound up'	
Most of the time	
A lot of the time	
From time to time, occasionally	
Not at all	

2. I still enjoy the things I used to enjoy	
Definitely as much	
Not quite so much	
Only a little	
Hardly at all	

3. I get a sort of frightened feeling as if something awful is about to happen	
Very definitely and quite badly	
Yes, but not too badly	
A little, but it doesn't worry me	
Not at all	

4. I can laugh and see the funny side of things	
As much as I always could	
Not quite so much now	
Definitely not so much now	
Not at all	

---

5. Worrying thoughts go through my mind

A great deal of the time

A lot of the time	
-------------------	--

From time to time, but not too often

Only occasionally	
-------------------	--

---

6. I feel cheerful

Not at all

Not often	
-----------	--

Sometimes

Most of the time	
------------------	--

---

7. I can sit at ease and feel relaxed

Definitely

Usually	
---------	--

Not Often

Not at all	
------------	--

---

8. I feel as if I am slowed down

Nearly all the time

Very often	
------------	--

Sometimes

Not at all	
------------	--

---

9. I get a sort of frightened feeling like 'butterflies' in the stomach

Not at all

Occasionally	
--------------	--

Quite Often

Very Often	
------------	--

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10. I have lost interest in my appearance

Definitely

I don't take as much care as I should	
---------------------------------------	--

I may not take quite as much care

I take just as much care as ever	
----------------------------------	--

---

11. I feel restless as I have to be on the move

Very much indeed

Quite a lot	
-------------	--

Not very much

Not at all	
------------	--

---

12. I look forward with enjoyment to things

As much as I ever did

Rather less than I used to	
----------------------------	--

Definitely less than I used to

Hardly at all	
---------------	--

---

13. I get sudden feelings of panic

Very often indeed

Quite often	
-------------	--

Not very often

Not at all	
------------	--

---

14. I can enjoy a good book or radio or TV programme

Often

Sometimes	
-----------	--

Not often

Very seldom	
-------------	--

### Health Anxiety

This questionnaire is asking about a *general tendency* to worry about one's health, so the questions do not necessarily relate to worries about Parkinson's disease (PD).

Each question in this section consists of a group of four statements. Please read each group of statements carefully and then select the one which best describes your feelings, over the **past six months**. Identify the statement by **circling the letter next to it** e.g. if you think that statement (a) is correct, circle statement (a); it may be that more than one statement applies, in which case, please circle any that are applicable.

- 1      (a)      I do not worry about my health  
         (b)      I occasionally worry about my health  
         (c)      I spend much of my time worrying about my health  
         (d)      I spend most of my time worrying about my health
  
- 2      (a)      I notice aches/pains less than other people (of my age)  
         (b)      I notice aches/pains as much as most other people (of my age)  
         (c)      I notice aches/pains more than most other people (of my age)  
         (d)      I am aware of aches/pains in my body all the time
  
- 3      (a)      As a rule I am not aware of bodily sensations or changes  
         (b)      Sometimes I am aware of bodily sensations or changes  
         (c)      I am often aware of bodily sensations or changes  
         (d)      I am constantly aware of bodily sensations or changes
  
- 4      (a)      Resisting thoughts of illness is never a problem  
         (b)      Most of the time I can resist thoughts of illness  
         (c)      I try to resist thoughts of illness but I am often unable to  
         (d)      Thoughts of illness are so strong that I no longer even try to resist  
         them

- 5 (a) As a rule I am not afraid that I have a serious illness [other than PD]  
(b) I am sometimes afraid that I have a serious illness [other than PD]  
(c) I am often afraid that I have a serious illness [other than PD]  
(d) I am always afraid that I have a serious illness [other than PD]
- 6 (a) I do not have images (mental pictures) of myself being ill  
(b) I occasionally have images of myself being ill  
(c) I frequently have images of myself being ill  
(d) I constantly have images of myself being ill
- 7 (a) I do not have any difficulty taking my mind off thoughts about my health  
(b) I sometimes have difficulty taking my mind off thoughts about my health  
(c) I often have difficulty taking my mind off thoughts about my health  
(d) Nothing can take my mind off thoughts about my health
- 8 (a) I am lastingly relieved if my doctor tells me there is nothing wrong  
(b) I am initially relieved but worries sometimes return later  
(c) I am initially relieved but the worries always return later  
(d) I am not relieved if my doctor tells me there is nothing wrong
- 9 (a) If I hear about an illness, other than PD, I never think I have it myself  
(b) If I hear about an illness, other than PD, I sometimes think I have it myself  
(c) If I hear about an illness, other than PD, I often think I have it myself  
(d) If I hear about an illness, other than PD, I always think I have it myself



- 10 (a) If I have a bodily sensation or change I rarely wonder what it means  
(b) If I have a bodily sensation or change I often wonder what it means  
(c) If I have a bodily sensation or change I always wonder what it means  
(d) If I have a bodily sensation or change I must know what it means
- 11 (a) I usually feel at very low risk for developing a serious illness [other than PD]  
(b) I usually feel at fairly low risk of developing a serious illness [other than PD]  
(c) I usually feel at moderate risk for developing a serious illness [other than PD]  
(d) I usually feel at high risk of developing a serious illness [other than PD]
- 12 (a) I never think I have a serious illness, other than PD  
(b) I sometimes think I have a serious illness, other than PD  
(c) I often think I have a serious illness, other than PD  
(d) I usually think that I am seriously ill with something other than PD
- 13 (a) If I notice an unexplained bodily sensation I never do anything to try and get rid of it  
(b) If I notice an unexplained bodily sensation I sometimes try to get rid of it  
(c) If I notice an unexplained bodily sensation I often try to get rid of it  
(d) If I notice an unexplained bodily sensation I always try to get rid of it

- 14      (a)      My family/friends would say I do not worry enough about my health  
            (b)      My family/friends would say I have a normal attitude to my health  
            (c)      My family/friends would say I worry too much about my health  
            (d)      My family/friends would say I am a hypochondriac

## IUS

You will find below a series of statements which describe how people may react to the uncertainties of life. Please use the scale below to describe to what extent each item is characteristic of you. **Please circle a number (1 to 5) that describes you best.**

	Not at all characteristic of me	A little characteristic of me	Somewhat characteristic of me	Very characteristic of me	Entirely characteristic of me
1. Unforeseen events upset me greatly	1	2	3	4	5
2. It frustrates me not having all the information I need.	1	2	3	4	5
3. Uncertainty keeps me from living a full life.	1	2	3	4	5
4. One should always look ahead so as to avoid surprises.	1	2	3	4	5
5. A small unforeseen event can spoil everything, even with the best of planning.	1	2	3	4	5
6. When it's time to act, uncertainty paralyzes me.	1	2	3	4	5
7. When I am uncertain I can't function very well.	1	2	3	4	5
8. I always want to know what the future has in store for me.	1	2	3	4	5
9. I can't stand being taken by surprise.	1	2	3	4	5
10. The smallest doubt can stop me from acting.	1	2	3	4	5
11. I should be able to organize everything in advance.	1	2	3	4	5
12. I must get away from all uncertain situations.	1	2	3	4	5

**Ferrans and Powers**  
**QUALITY OF LIFE INDEX®**  
**STROKE VERSION - III**

**PART 1.** For each of the following, please choose the answer that best describes how *satisfied* you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

<b>HOW SATISFIED ARE YOU WITH:</b>	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. The amount of pain that you have?	1	2	3	4	5	6
4. The amount of energy you have for everyday activities?	1	2	3	4	5	6
5. Your ability to do things for yourself?	1	2	3	4	5	6
6. Your ability to get around (for example, to walk or use a wheelchair)?	1	2	3	4	5	6
7. Your ability to go places outside your home?	1	2	3	4	5	6
8. Your ability to speak?	1	2	3	4	5	6
9. The amount of control you have over your life?	1	2	3	4	5	6
10. Your chances of living as long as you would like?	1	2	3	4	5	6
11. Your family's health?	1	2	3	4	5	6
12. Your children?	1	2	3	4	5	6
13. Your family's happiness?	1	2	3	4	5	6
14. Your spouse, lover, or partner?	1	2	3	4	5	6
15. Your sex life?	1	2	3	4	5	6
16. Your friends?	1	2	3	4	5	6

(Please Go To Next Page)

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HOW <i>SATISFIED</i> ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
17. The emotional support you get from your family?	1	2	3	4	5	6
18. The emotional support you get from people other than your family?	1	2	3	4	5	6
19. Your ability to take care of family responsibilities?	1	2	3	4	5	6
20. How useful you are to others?	1	2	3	4	5	6
21. The amount of worries in your life?	1	2	3	4	5	6
22. Your neighborhood?	1	2	3	4	5	6
23. Your home, apartment, or place where you live?	1	2	3	4	5	6
24. Your job (if employed)?	1	2	3	4	5	6
25. Not having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
26. Your education?	1	2	3	4	5	6
27. How well you can take care of your financial needs?	1	2	3	4	5	6
28. The things you do for fun?	1	2	3	4	5	6
29. Your chances for a happy future?	1	2	3	4	5	6
30. Your peace of mind?	1	2	3	4	5	6
31. Your faith in God?	1	2	3	4	5	6
32. Your achievement of personal goals?	1	2	3	4	5	6
33. Your happiness in general?	1	2	3	4	5	6
34. Your life in general?	1	2	3	4	5	6
35. Your personal appearance?	1	2	3	4	5	6
36. Yourself in general?	1	2	3	4	5	6

(Please Go To Next Page)

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**PART 2.** For each of the following, please choose the answer that best describes how *important* that area of your life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. Having no pain?	1	2	3	4	5	6
4. Having enough energy for everyday activities?	1	2	3	4	5	6
5. To be able to do things for yourself?	1	2	3	4	5	6
6. To be able to get around (for example, to walk or use a wheelchair)?	1	2	3	4	5	6
7. To go places outside your home?	1	2	3	4	5	6
8. To be able to speak?	1	2	3	4	5	6
9. Having control over your life?	1	2	3	4	5	6
10. Living as long as you would like?	1	2	3	4	5	6
11. Your family's health?	1	2	3	4	5	6
12. Your children?	1	2	3	4	5	6
13. Your family's happiness?	1	2	3	4	5	6
14. Your spouse, lover, or partner?	1	2	3	4	5	6
15. Your sex life?	1	2	3	4	5	6
16. Your friends?	1	2	3	4	5	6
17. The emotional support you get from your family?	1	2	3	4	5	6

(Please Go To Next Page)

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Page 3

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
18. The emotional support you get from people other than your family?	1	2	3	4	5	6
19. Taking care of family responsibilities?	1	2	3	4	5	6
20. Being useful to others?	1	2	3	4	5	6
21. Having no worries?	1	2	3	4	5	6
22. Your neighborhood?	1	2	3	4	5	6
23. Your home, apartment, or place where you live?	1	2	3	4	5	6
24. Your job (if employed)?	1	2	3	4	5	6
25. Having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
26. Your education?	1	2	3	4	5	6
27. Being able to take care of your financial needs?	1	2	3	4	5	6
28. Doing things for fun?	1	2	3	4	5	6
29. Having a happy future?	1	2	3	4	5	6
30. Peace of mind?	1	2	3	4	5	6
31. Your faith in God?	1	2	3	4	5	6
32. Achieving your personal goals?	1	2	3	4	5	6
33. Your happiness in general?	1	2	3	4	5	6
34. Being satisfied with life?	1	2	3	4	5	6
35. Your personal appearance?	1	2	3	4	5	6
36. Are you to yourself?	1	2	3	4	5	6

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